

EXPLORING THE SERVICE EXPERIENCES OF WOMEN WITH AUTISM
SPECTRUM DISORDER: A MIXED-METHODS STUDY

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ABSTRACT

Individuals with Autism Spectrum Disorder (ASD) often have complex service needs across the lifespan. The specific experiences of women with ASD, however, remain largely unknown. This concurrent mixed-methods dissertation consists of one quantitative study and one qualitative study examining the service experiences of women with ASD; integration occurred in a separate deductive, latent-level analysis.

Study 1 used data from the Canadian Autism Spectrum Disorder Alliance National Needs Survey, and provides a descriptive analysis of lifetime service use, unmet service needs, and barriers to care of a sample of Canadian adults with ASD, the majority of whom did not report a co-occurring intellectual disability (ID). Few significant sex/gender differences emerged, with the exception of mental health and residential services. However, a number of significant associations between service outcome variables and micro, meso, and exo system factors were found.

Study 2 is a qualitative study comprised of five focus groups of 20 women with ASD without ID with discussions centered on their service use, unmet service needs, and barriers to care. Overall, women emphasized high unmet service needs, particularly with respect to mental health concerns, residential supports, and vocational and employment services. Participants also perceived many service providers as disregarding or misunderstanding the female presentation of ASD and associated unique service needs.

Results from the two studies were integrated in a latent level analysis, incorporating ecological and postcolonial feminist frameworks. The project's findings are discussed in relation to areas of future research required to ensure effective care for this understudied population.

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PUBLICATION DISCLOSURE

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Chapter 1: Introduction

Recent international policies prioritize service provision for adults with Autism Spectrum Disorder (ASD; Ministry of Community and Social Services Partnership Table Housing Study Group, 2013; National Audit Office, 2009; Select Committee on Developmental Services, 2014; U.S. Department of Health and Human Services Interagency Autism Coordinating Committee, 2012). The literature to date, however, is focused on an understanding of the service needs of the young male profile of ASD (Edwards, Watkins, Lotzfideh, & Poling, 2012; Kirkovski, Enticott, & Fitzgerald, 2013; Kreiser & White, 2014; Watkins, Zimmerman, & Poling, 2014). While past research in the broader intellectual and/or developmental disability (IDD) literature suggests women with IDD are faced with both sex/gender¹ and disability related barriers to care (Boeltzig, Timmons, & Butterworth, 2009; Brown & Gill, 2009; Cobigo et al., 2013; Havercamp, Scandlin, & Roth, 2004; Parish & Saville, 2006; Reynolds, Stanistreet, & Elton, 2008; Swaine, Dababnah, Parish, & Luken, 2013; Taggart, Truesdale-Kennedy, & McIlpatrick, 2011), the experiences of women with ASD remain largely unknown. Using a mixed methods approach, this project explored the service needs, barriers to care, and service experiences of women with ASD. A better understanding of their experiences may help to ensure equitable access to effective service provision.

¹ The term sex/gender is used to acknowledge the intersection of sex-specific biological and physiological characteristics with gendered socialization processes (Lai et al., 2015; Springer, Stellman, & Jordan-Young, 2012).

Female Profile of ASD

The prevailing male focus in ASD literature is commonly attributed to the predominance of males diagnosed with the disorder (Holtmann, Bolte, & Poutska, 2007; Krahn & Fenton, 2012; Watkins et al., 2014). Recent estimates suggest one in 68 children in the United States are identified with ASD, with boys almost four times more likely to be affected than girls (Center for Disease and Control Prevention, 2014; Loomes, Hull, & Mandy, 2017). While limited, preliminary evidence indicates prevalence rates of adults with ASD parallel those in children (Brugha et al., 2011). Male to female ratios, however, vary considerably across epidemiological and clinical population studies and fluctuate greatly according to language and cognitive abilities (Baio, 2012; Carter et al. 2007, Fombonne, 2003, 2009; Jensen, Steinhausen, & Lauritsen, 2014; Kim et al., 2011; Kuehn, 2007; Loomes et al., 2017; Mandy et al., 2012; McLennan, Lord, & Schopler, 1993; Mattila et al., 2011; Mayes & Calhoun, 2011; Scott, Baron-Cohen, Bolton, & Brayne, 2002; Zwaigenbaum et al., 2012). For instance, male to female invariances decrease to 2:1 in children with ASD and severe cognitive impairments and increase as high as 10:1 in individuals with Asperger syndrome, a DSM IV subtype of ASD without language impairment or intellectual disability (ID; Fombonne, 2009). A wide range of hypotheses regarding the etiology of the sex/gender differences in ASD prevalence rates have been proposed, including genetic, neuroanatomical, and hormonal influences, as well as the validity and sensitivity of current assessment measures (e.g., Auyeung et al., 2009; Baron-Cohen et al., 2015; Baron-Cohen, Knickmeyer, & Belmonte, 2005; Bloss & Courchesne, 2007; Chen, Van Horn, & GENDAAR Research Consortium, 2016; Dworzynski, Ronald, Bolton, & Happe, 2012; Sebat et al., 2007; Zhao et al., 2007).

Research has also increasingly explored the possibility of sex/gender differences in the manifestation of clinical symptoms that may account, in part, for male to female prevalence invariances (Begeer et al., 2013; Carter et al., 2007; Dworzynski et al., 2012; Frazier, Georgiades, Bishop, & Hardan, 2014; Harrop et al., 2015; Hiller, Young & Weber, 2014; 2016; Kirokovski et al., 2013; Kopp & Gillberg, 2011; Kumazaki et al., 2015; Lai et al., 2012; Mandic-Maravic et al., 2015; Mayes & Calhoun, 2011; McLennan et al., 1993; Reinhardt, Wetherby, Schatschneider, & Lord, 2015). Autism Spectrum Disorder diagnosis is made at the behavioral level with a focus on impairments in social-communication and restrictive or stereotyped behaviors and interests (American Psychiatric Association, 2013). While results to date vary considerably across individual studies, a meta-analysis of 22 peer reviewed publications found males and females with ASD showed similar symptom severity on communication and social behavior; however, females showed less restricted interests and stereotyped behaviors than males (Van Wijngaarden-Cremers et al., 2014). However, it has also been suggested that girls with ASD may have more socially accepted restricted or stereotyped interests and behaviors and thus be under identified (Kopp & Gillberg, 1992). For instance, Hiller et al. (2016) described caregiver and teacher reports of girls with ASD without ID to include complex imitation and circumscribed interests in objects like dolls, rather than parts of toys as typically described of boys with ASD. Anecdotal reports further suggest the seemingly typical circumscribed interests of girls with ASD may be misinterpreted as pretend play (Halladay et al., 2015).

Clinical observations highlight how some girls with ASD may develop strategies to cope or adapt to certain situations, subsequently “camouflaging” their symptoms

(Attwood, 2007; Bargiela, Steward, & Mandy, 2016; Hull et al., 2017; Kopp & Gillberg, 1992; Lehnhardt et al., 2016; Tierney, Burns & Kilbey, 2016). That is, girls and women with ASD may mask behavior viewed as socially unacceptable and/or imitate others' social behavior, such as engaging in eye-contact during conversation and using social scripts (Bargiela et al., 2016; Hull et al., 2017; Lai & Baron-Cohen, 2015; Tierney et al., 2016). Recent work by Lai et al. (2017) aimed to quantify these abilities of adults with ASD without ID. Specifically, camouflaging was quantified as the discrepancy between an individual's external behavioral presentation during social interactions (as measured by the Autism Diagnostic Observation Schedule; Lord, Risi, & Lambrecht, 2000) and the individual's internal characteristic traits (measured by the Autism Spectrum Quotient; Baron-Cohen et al., 2001), and social cognitive capability (measured by the Reading the Mind in the Eyes Test; Baron-Cohen et al., 2015). On average, women had higher camouflage scores than men (Lai et al., 2017). Further speaking to the hypothesis that girls with ASD may (knowingly or not) develop greater compensatory strategies or skills to "hide" their impairments in certain settings, females have been shown to have better-developed imaginative play (Attwood, 2012; Knickmeyer, Wheelwright & Baron-Cohen, 2008; Solomon, Miller, Taylor, Hinshaw, & Carter, 2012) and show more interest in social relations than males (Attwood, 2007; Baron-Cohen et al., 2011; Hsiao, Tseng, Huang, & Gau, 2013; Rivet & Matson, 2011). Similarly, females with ASD without ID tend to have greater verbal fluency, nonverbal modes of communication (e.g., use of gestures), processing speed, and cognitive flexibility as compared to males with ASD without ID (Goddard, Dritschel, & Howlin, 2014; Lai et al., 2011; Lenhardt et al., 2016; Memari et al., 2013; Rynkiewicz et al., 2016; Zwaigenbaum et al., 2012).

Age and developmental factors may also play a role in sex/gender differences. A recent eye-tracking study (Chawarska, Macari, Powell, DiNicola, & Shic, 2016) involving 6, 9 and 12 month old infants at high genetic risk for ASD (i.e., infants who have a sibling with ASD) demonstrated that high-risk females showed increased social attention to social targets compared to both high-risk males and low-risk males and females; however, other studies have demonstrated no significant differences in behavioral features in children with ASD 2 to 5 years of age (Postorino et al., 2015; Reinhardt et al., 2015). Among an adult sample of individuals with ASD, Lai et al. (2011) failed to identify sex/gender-related differences during childhood based on caregivers' retrospective report; however, clinical assessment of present day ASD symptomatology suggested greater socio-communicative ability among the female subsample. A lack of significant sex/gender differences in young children with ASD may be attributable to typical social communication developmental trajectories. That is, in the typically developing population, discrepancies in social skills between males and females differ across development (Rose & Rudolph, 2006). It is possible that ASD symptoms may not emerge in females until the social milieu becomes more complex in adolescence and deficits in social skills are known to become increasingly pronounced (Hsiao et al., 2013; Kopp & Gillberg, 2011; Tantam, 2000; White, Keonig, & Scahill, 2007). To this end, in a Scottish sample of children and adults recently diagnosed with ASD (Rutherford et al., 2016), the sex ratio was shown to increase with age, with smaller sex invariances for adolescents (2.3 male: 1 female) than for younger children (5.5 male: 1 female).

Perhaps related to an atypical clinical presentation, many females with ASD without ID often receive delayed or misdiagnoses (Attwood, 2012; Bargiela et al., 2016;

Begeer et al., 2013; Dworzynski et al., 2012; Cridland, Jones, Caputi, & Magee, 2014; Goin-Kochel, Mackintosh, & Myers, 2006; Kreiser & White, 2013; Nichols, Moravick, & Tetenbaum, 2009; Russel, Steer, & Golding, 2010; Rutherford et al., 2016; Shattuck et al., 2009; Solomon et al., 2012; Wiggins, Baio, & Rice, 2006). Current assessment measures, which were normed with predominantly male samples, may not be sensitive to female presentations of ASD (Begeer et al., 2013; Dworzynski et al., 2012; Kirokovski et al., 2013; Kopp & Gillberg, 1992; Lai et al., 2011). Moreover, public and professional ascertainment bias may lead many families and clinicians to misinterpret female symptoms of ASD, resulting in improper referrals and misdiagnoses (Howe, Yatchmink, Viscidi, & Morrow, 2014; Mandy et al., 2012). For instance, in a secondary analysis of population-based data of 8-year-olds from the United States, girls with ASD were less likely to have received a diagnosis in the community than boys, despite meeting diagnostic criteria on independent educational and developmental service file review (Giarelli et al., 2010). In an Australian qualitative study (Cridland et al., 2014), four of five mothers of adolescent daughters with ASD considered the diagnostic process to be more difficult for girls when comparing their personal experiences with those of friends who have boys with ASD. Reasons for their difficulties included their daughters' untraditional presentation of symptoms, health professionals' general lack of awareness of ASD in girls and overall reluctance to provide formal diagnoses.

Service Needs and Experiences of Women with ASD

Recent research highlights the difficulties that many girls with ASD encounter during the diagnostic process (e.g., Cridland et al., 2014); however, their broader service experiences across the lifespan are largely unknown. Individuals with ASD have complex

care needs, often requiring many services across different sectors (Boulet, Boyle, & Schieve, 2009; Croen, Najjar, Ray, Lotspeich, & Bernal, 2006; Gerhardt & Lainer, 2011). Studies investigating the service experiences of adults with ASD from their own perspectives, however, are relatively few in number (e.g., Griffith et al., 2012; Nicolaidis et al., 2013; Vogan et al., 2017) and do not provide detailed examination of women's specific needs and experiences.

In addition to the previously discussed sex/gender-specific concerns with assessment and diagnosis services, past research has highlighted an additional five broad domains of services for individuals with ASD and typically developing women where studying the experiences of women with ASD is particularly warranted: 1) physical health care; 2) mental health care; 3) social skills supports; 4) postsecondary educational, vocational, and employment services; and 5) residential supports.

Medical service needs and experiences. Compared to typically developing children, children with ASD have poorer health and require more specialized care for common comorbidities such as dental problems, sleep problems, seizures, gastrointestinal problems, and food and skin allergies (Canitano, Luchetti, & Zappella, 2005; Gurney et al., 2006; Lai, Milano, Roberts, & Hoopers, 2012; Molloy & Manning-Courtney, 2003). Fewer studies in comparison, however, have studied the health of adults (Jennes-Coussens, Magill-Evans, & Koning, 2006; Kamp-Becker, Schroder, Remschmidt, & Bachmann, 2010; Khanna, Jariwala-Parikh, West-Strum, & Mahabaleshwarkar, 2014; Tyler, Schramm, Karafa, Tang, & Jain, 2011). In the first study to include a broad age range of adults with ASD with varied intellectual functioning ($N=1507$), Croen et al. (2015) found many common medical conditions were more prevalent in adults with ASD

as compared to typically developing controls, including immune conditions, gastrointestinal and sleep disorders, seizure disorders, obesity, dyslipidemia, hypertension, and diabetes. Adults with ASD also had a significantly higher prevalence of rarer medical conditions, such as stroke, Parkinson's disease, vitamin deficiencies, and vision and hearing impairments. All medical conditions were diagnosed more frequently among women with ASD compared to men with ASD, with the exception of lower gastrointestinal conditions, Hepatic disease and genitourinary disorders.

Women with ASD are also at an increased risk of presenting with higher rates of female specific physical health conditions than women without ASD (Ingudomnukul, Baron-Cohen, Wheelwright, & Knickmeyer, 2007; Knickmeyer, Wheelwright, Hoekstra, & Baron-Cohen, 2007; Pohl, Cassidy, Auyeung, & Baron-Cohen, 2014). Girls with ASD experience high rates of early and delayed onset of puberty and a host of menstrual difficulties, including premenstrual syndrome, amenorrhea, and dysmenorrhea (Ingudomnukul et al., 2007; Knickmeyer et al., 2007). Menstrual difficulties for girls and women with ASD may be further compounded by challenges with self-care and resulting hygiene concerns (Cridland et al., 2014; Hamilton, Marshall, Murray, & Murray, 2011). Although there is a more limited literature base on sex-specific health concerns for adult women with ASD, qualitative research details the sensory challenges some women experience associated with pregnancy and childbirth (Gardner, Suplee, Bloch, & Lecks, 2016; Lum, Garnett, & O'Connor, 2014).

Despite these high needs, families of children with ASD consistently report a higher occurrence of unmet medical needs and lower satisfaction ratings with care as compared to families of typically developing children and children with other special

health needs (Chiri & Warfield, 2011; Croen et al., 2006; Gurney et al., 2006; Kogan et al., 2008; Krauss, Gulley, Sciegaj, & Wells, 2003; Liptak, Stuart, & Auigner, 2006), and similar findings are evident in the adult ASD literature (Nicolaidis et al., 2013; Shattuck, Wagner, Narendorf, Sterzing, & Herzing, 2011). In an American study using a community participatory action based research design, Nicolaidis et al. (2013) compared the healthcare experiences of 209 adults with ASD (59% female) and 228 adults without ASD (66% female) via an online survey. Individuals with ASD self-reported greater unmet healthcare needs and lower utilization of preventative services than adults without ASD, including Papanicolaou tests among women. Adults with ASD also reported lower satisfaction with patient-provider communication and lower ratings of perceived health care self-efficacy. Nicolaidis and colleagues' (2013) satisfaction and healthcare self-efficacy analyses, however, did not account for possible sex/gender differences among individuals with ASD or differentiate specific healthcare experiences among women.

In the broader IDD literature, women have been shown to experience broad inequities in access to health services (Broughton & Thomson, 2000; Brown, Plourde, Ouellette-Kuntz, Vigod & Cobigo, 2016; Cobigo et al., 2013; Haverkamp et al., 2004; Parish & Saville, 2006; Reynolds, Stanistreet, & Elton, 2008). Many women with IDD may be at an increased risk of developing reproductive cancers (Davies & Duff, 2001; Seltzer, Schupf & Wu, 2001); however, they are less likely than women without IDD to have preventive screenings (Broughton & Thomson, 2000; Cobigo et al., 2013). In a population based study of women in Ontario, Cobigo et al. (2013) reported that the proportion of women with IDD who are not screened for breast cancer is nearly 1.5 times the proportion of women without IDD, and the proportion of women with IDD who are

not screened for cervical cancer is nearly twice the proportion of women without IDD. Historically, women with IDD have been subjected to a denial of medical services as well as treatment without consent, including concealed contraception, involuntary sterilization and abortion (Block, 2000). Many have been denied adequate access to information on sexual health, pregnancy and parenting (Gill & Brown, 2000). Further, while Canada is one of only a handful of countries to have practice parameters with specific recommendations for primary medical care of adults with IDD (Sullivan et al., 2011), the health service experiences of Canadian women with ASD remain largely unknown.

Mental health service needs and service experiences. Individuals with ASD are, at all ages, at greater risk for developing mental health problems than the general population (Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998; Morgan, Roy, & Chance, 2003), as well as compared to individuals with ID without ASD (Bradley, Summer, Wood, & Bryson, 2004; Brereton, Tonge, & Einfled, 2006; McClintock, Hall & Oliver, 2003). Girls with ASD may be more likely than boys to develop a clinically elevated and stable trajectory of internalizing symptoms in early childhood (Vaillancourt et al., 2017), with some studies showing similar findings in late childhood and adolescence (Mandy et al., 2012; Oswald et al., 2016; Solomon et al., 2012). However, other studies have not found sex/gender differences in co-occurring psychiatric disorders across childhood or adolescence (Howe et al., 2015; Pisula et al., 2017), and results are inconsistent with respect to adulthood (Croen et al., 2015; Hofvander et al., 2009; Lugnegård, Hallerbäck, & Gillberg, 2009; Woodman, Mailick, & Greenberg, 2016). Some women, particularly those without ID, may not receive an appropriate ASD diagnosis due to diagnostic overshadowing (i.e., misattributing ASD features to

previously diagnosed psychiatric conditions, such as eating and personality disorders; Kirkovski et al., 2013; Luciano et al., 2014; Mandy & Tchanturia, 2015). Additionally, late identification of ASD in itself is also frequently associated with negative psychological repercussions for many women (Bargiela et al., 2016). Women diagnosed with ASD as adults often recall many stressful life experiences throughout their childhood resulting in a lack of self-understanding, which may negatively influence self-identity formation (Kanfiszer, Davies, & Collins, 2017).

Similar to medical services, families of children with ASD consistently report dissatisfaction with mental health services and pervasive unmet mental health needs (Brookman-Frazee, Baker-Ericzen, Stadnick, & Taylor, 2012). Likewise, accessing appropriate mental health care for adults with IDD has been seen as a systemic health inequity in Canada, where service provision does not adequately meet the need (Lunsky, Garcin, Morin, Cobigo, & Bradley, 2007; Ouellette-Kuntz et al., 2005). Further, when mental health services are accessible, they may not always suit the unique needs of adults with ASD (Hare, Pratt, Burton, Bromley & Emerson, 2004; Griffith et al., 2012). For example, in a qualitative study involving adults with ASD without ID, participants described their difficulties with depression and anxiety and their dissatisfaction with “mainstream” therapies (i.e., cognitive behavioral therapies; Griffith et al., 2012). In the absence of available and/or appropriate mental health services, adults with ASD have been identified as disproportionately high users of emergency department psychiatric services (Iannuzzi, Cheng, Broder-Fingert, & Bauman, 2015; Vohra, Madhavan, & Sambamoorthi, 2016), and a recent study demonstrated female adolescents and adults with ASD are more likely to have psychiatric concerns and to visit the emergency

department than their male counterparts (Tint, Weiss, & Lunsky, 2017). Given the possibility of sex/gendered presentations of psychopathology and responses to pharmacological agents and therapeutic interventions (Robles et al., 2014; Thompson, Caruso, & Ellerbeck, 2003), further research is needed to fully understand the mental health service experiences of women with ASD.

Social skills service needs and service experiences. Deficits in social skills are a hallmark feature of ASD (Carter, Davis, Klin, & Volkmar, 2005). While the presentation of social deficits may significantly differ according to individuals' levels of cognitive and language abilities (Bauminger, Shulman, & Agam, 2003), social use of language, interpretation of social information, and participation in reciprocal social interaction often continue to be areas of significant difficulty for adults with ASD (Farley et al., 2009; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). Poor social skills in adults with ASD are thought to be significant contributors to high levels of loneliness, few romantic relationships, and low rates of independent living and employment (Billstedt, Gillberg, & Gillberg, 2007; Farley et al., 2009; Howlin, Goode, Hutton, & Rutter, 2004). Social impairments may also contribute to the high rates of financial and sexual exploitation among adults with IDD, especially among women (Balfe & Tantam, 2010; Brown-Lavoie, Vecili, & Weiss, 2014; Howlin, 2000; Sperry & Mesibov, 2005; Wacker, Macy, Barger, & Parish, 2009).

Women with ASD may face unique social challenges, differing from those experienced by men with ASD. Consistent with typically developing children, children with ASD have also been shown to demonstrate a preference for same sex friendships (Dean et al., 2014; Kasari, Locke, Gulrad, & Rotherham-Fuller, 2011). Specific social

challenges for girls with ASD may include the implicit social intimacy and high language demands that characterize female friendships (Dean, Adams, & Kasari, 2013; Maccoby, 2002). Girls with ASD may be more inclined to form male-typical relationships, which are often less socially complex and formed on the basis of companionship activities (Bauminger et al., 2004; Carrington, Templeton, & Papinczak, 2003). Adolescent girls with ASD have described their difficulties following conversations, not fitting in due to dissimilar interests, and nuanced forms of relational aggression (Cridland et al., 2014; Nichols et al. 2009; Sedgewick, Hill, Yates, Pickering, & Pellicano, 2016; Solomon et al., 2012; Tierney et al., 2016). Research on the social experiences of women with ASD is limited; however, it has been suggested that women with ASD continue to experience considerable social difficulty across the lifespan. For instance, in a sample of 122 adults with ASD without ID in France and Sweden, more women than men reported experiences of peer victimization (Hofvander et al., 2009). Similarly, in an online Australian study surveying the experiences of 82 women with ASD without ID, almost one quarter of women mentioned incidents of bullying and/or overt mistreatment in the workplace (Baldwin & Costley, 2016).

Social skill interventions are a commonly used service among children with ASD (Reichow & Volkmar, 2010). Although services differ according to ability, commonly covered topics include emotion identification and regulation, social problem solving and communication skills (Reichow & Volkmar, 2010). Adults with ASD have spoken about their needs for greater individualized social supports, facilitated social interactions, and explicit instruction in social cues (Muller, Schuler, & Yates, 2008). Psychosocial intervention for adults with ASD, however, is a relatively new area of research and the

existing evidence base is limited (Bishop-Fitzpatrick, Minshew, & Each, 2013). Further, sex/gender-specific social skills services may be needed for women with ASD, given the unique social issues they may face (Dean et al., 2013; Head, McGillivray, & Stokes, 2014; Nichols et al., 2009; Ranson & Byrne, 2014).

Employment, education and day service needs and service experiences. After leaving high school, adults with ASD lose mandated special education services and enter adult service sectors that often have long waiting lists (Prouty, Alba, Smith, & Lakin, 2006). Studies have found that 12 to 24% of young adults with ASD are not engaged in any productive day activities after leaving high school (Cederlund, Hagberg, Billstedt, Gillberg, & Gillberg, 2008; Shattuck et al., 2012, Taylor & Seltzer, 2011). Among individuals with ASD without ID, rates of postsecondary attendance and degree attainment are substantially lower than the general population, despite many graduating from mainstream high school classrooms (Cedurlund et al., 2008; Eaves & Ho, 2008; Howlin, 2005). Employment outcomes, including volunteer and supported employment, are also poor among adults with ASD with odds of employment significantly less than typically developing peers, individuals with less severe language disorders, and individuals with ID without ASD (Howlin, 2000; Jennes-Coussens, Magill-Evans, & Koning, 2006; Muller, Schuler, Burton, & Yates, 2003; Roux et al., 2013; Shattuck et al., 2012). Past research has shown that young women with IDD are less likely to be employed compared to men with IDD, and, if they are employed, are more likely to work in low skill/status jobs for fewer hours and less pay (Boeltzig et al., 2009). Similarly, in a study focusing on longitudinal employment patterns of adults with ASD without ID

(Taylor, Henninger, & Mailick, 2015), women were less likely to maintain employment as compared to men.

Disorder-specific challenges, such as sensory sensitivities, poor organizational and planning skills, as well as secondary problems, like those associated with comorbid mental health problems, may prevent many adults with ASD from achieving their academic or vocational potential (White, Ollendick, & Bray, 2011). Past research has shown many women, in comparison to men, with disabilities may lack the requisite self-confidence or communication skills to actively seek information or direct their own career and educational development process (Lindstrom, Harwick, Poppen, & Doren, 2012). Many individuals with ASD are capable of attending post-secondary education and/or working if provided with the necessary supports, such as academic tutoring, classroom accommodations, vocational skill training, job coaching and on-site supervision (Gerhardt & Holmes 2005; Van Bergeijk, Klin, & Volkmar, 2008). Adults with ASD, however, have described vocational and educational supports as highly ineffective due to a lack of specialized training and knowledge of their specific needs (Baldwin & Costley, 2016; Griffith et al., 2012; Muller et al., 2003; Nicholas, Attridge, Zwaigenbaum, & Clarke, 2015; Richards, 2012). In one of the few studies to date to examine sex/gender differences in vocational support services among individuals with ASD, Sung, Sánchez, Kuo, Wang, and Leahy (2015) reported job placement and on-the-job supports to be significant predictors of successful competitive employment among both male and female transition-aged youth. Males with ASD also benefited from counselling and guidance services, job search assistance services, and other support

services (e.g., occupational licenses, tools and equipment); however, there were no additional sex/gender-specific service predictors for females.

Residential support service needs and service experiences. Many adults with ASD live with their families well into adulthood (Anderson, Shattuck, Cooper, Roux, & Wagner, 2014; Taylor & Seltzer, 2010). In a study by Krauss, Seltzer, and Jacobson (2005), mothers reported greater benefits for their adult children with ASD who lived outside of the family home, whereas those who co-resided reported negative consequences including lower ratings of contentment, not being pushed to be independent, and social isolation. Residential services in the adult developmental sector, however, are often costly or unavailable (Weeks, Nilsson, Bryanton, & Kozma, 2009). Further, some adults with IDD have described challenges in residential settings, such as a lack of privacy and loss of personal freedoms (e.g., living with assigned versus chosen staff and roommates; Gregory, Robertson, Kessissoglou, Emerson, & Hatton, 2001). In a Canadian study of parents of adults with IDD, families expressed a need for sex/gender-specific residential settings for their daughters (Weeks et al., 2009); however, overall research on residential service needs and experiences of adults with ASD is limited.

Barriers to Service Access and Use

Women with ASD report higher unmet care needs and less satisfaction with their service experiences than women without ASD (Lum et al., 2014; Nicolaidis et al., 2013). Contributing to these difficulties are individual and systemic barriers to effective care, which are often multilayered and interlinked (Raymaker et al., 2017). In addition to the general unavailability of adult ASD services, there are three main sources of service barriers documented in the extant literature that may be particularly relevant for women

with ASD: poor levels of service provider knowledge and skill, resource inequity, and sex/gender and disability-related bias.

Service provider knowledge and interactions. The complex care needs of individuals with ASD may pose challenges for affected individuals and service providers alike. Service providers have cited lack of training and comfort level as potential contributors to the lack of quality of care often available for patients with IDD (Burge, Ouellette-Kuntz, Isaacs, & Lunsky, 2008; Bruder, Kerins, Mazzarella, Sims, & Stein, 2012; Lunsky & Bradley, 2001; Nicolaidis et al., 2015; Warfield, Crossman, Delahaye, Der Weerd, & Kuhlthau, 2015; Weiss, Lunsky, & Morin, 2010; Zerbo, Massolo, Qian, & Croen, 2015). As part of a qualitative study in the United States, women with IDD expressed frustration at how little time their physicians spent with them as well as their desire for their physicians to speak directly to them, instead of to their support worker (Wilkinson, Dreyfus, Bowen, & Bokhour, 2013). On the other hand, physicians, often working under strict time constraints, felt that working with patients with IDD took too much time. With unique care needs in a service system that may be catered to the presentation of the disorder in men, a better understanding of how women with ASD perceive their interactions with service providers is needed.

Inequitable distribution of resources. In looking across individuals with ASD and service sectors, service access and utilization are not uniform. There appears to be an unequal distribution of services according to economic, ethnic and functional status (e.g., Lai & Weiss, 2017). Adults with ASD have service needs that span many different sectors and carry high and wide-ranging economic effects. In a nationally representative American telephone survey, caregivers reported young adults with ASD from lower

income households had higher odds of receiving no services compared to adults without ASD (Shattuck et al., 2011). Considering the lower earning potential of typically developing women and women with IDD alike (e.g., Boeltzig et al., 2009; Weichselbaumer & Winter-Ebner, 2005), women with ASD may also be more likely to live in lower income neighborhoods which may impact their service access. Further research is needed to understand potential financial barriers to services of women with ASD.

Similar associations have been found between race and ethnicity and service engagement in the adult ASD service literature. Shattuck et al. (2011) reported that African-American young adults with ASD, compared to white young adults with ASD, were 3.3 times more likely to not receive any services. Lower service utilization rates have also consistently been found among Latino and African-American children with ASD (Liptak et al., 2006; Mandell, Listerus, Levy, & Pinto-Martin, 2002; Rosenberg, Zhang, & Robinson, 2008). In the literature describing typically developing individuals, women of minority status have been shown to have decreased odds of having insurance and access to services than their white counterparts (e.g., Caplan, Wells, & Haynes, 1992); however, it remains unknown if race and ethnicity play a role in the service access experiences of Canadian women with ASD.

Indices of behavioral functioning such as ASD symptoms, maladaptive behaviors, and functional independence are also likely related to the service experiences of adults with ASD (Eaves & Ho, 2008; Howlin et al., 2004; Lai & Weiss, 2017; Shattuck et al., 2011; Taylor & Seltzer, 2011). Among a sample of 66 young adults with ASD who had recently graduated out of the school system in the U.S., Taylor and Seltzer (2011)

reported youth with ASD without ID were three times more likely to have no day activities than youth with ASD who had comorbid ID. Similarly, a high percentage of youth with maladaptive behaviors reported no daytime activities. Taylor and Seltzer (2011) posited that these findings are indicative of the adult service system's inadequate accommodation of the needs of adults with ASD without ID, as well as those with maladaptive behaviors. Indeed, many individuals with ASD without ID in Ontario are not eligible for services through the adult developmental service sector, despite exhibiting ASD related social and executive functioning deficits that significantly impact their lives (Burke & Stoddart, 2014). As some women with ASD demonstrate better developed social and communication abilities than men with ASD (e.g., Attwood, 2012), it is important to further understand their service experiences in a service system that may be better suited to meet the needs of those with more seemingly severe impairments.

Sex/gender and disability related biases. The social construction of gender and disability may also impede service access and use for women with ASD. According to Rousso and Wehmeyer (2001), women with disabilities experience the effects of the “double jeopardy” of both disability and gender. Across several different service domains, individuals with disabilities have been shown to struggle with ableism, defined as the assumptions and practices of discrimination, exclusion, and unequal treatment toward people with disabilities (Hehir, 2005). For example, negative perceptions of people with IDD have been shown to be present in a wide range of service providers, including employers (Ameri et al., 2015), nurses (Lewis & Stenfert-Kroese, 2010), medical students (Ouellette-Kuntz, Burge, Henry, Bradley, & Leichner, 2003), and attending physicians (Wilkinson et al., 2013). Adults with ASD have described their

hesitancy to disclose their diagnosis to healthcare providers due to perceived stigma around ASD and fear of discrimination (Nicolaidis et al., 2015). More generally, women are known to experience widespread forms of sexist discrimination (Landrine & Kolhoff, 1997), ranging from unjust work evaluations and salaries (Hakim, 2006) to inequitable service referrals, diagnosis, and treatment (Hartigan, 2001; Muller, 1990). For instance, health care professionals' have been shown to exhibit sex/gender stereotypes regarding women's responses to pain (e.g., a perceived tendency to overstate pain levels without an organic basis) and associated biased referral-decision making practices (Tobin et al., 1987).

Some authors have characterized women with disabilities as "roleless" because of the limited social roles available for them (Asch & Fine, 1992). Stereotyped as passive, asexual and dependent, women with disabilities are often not seen fit to fill the traditional female roles of a mother, wife and nurturer (Asch & Fine, 1992). At the same time, traditional male roles, such as provider and worker, are also deemed inappropriate (Asch & Fine, 1992). These socially constructed prejudices may pose barriers to women with disabilities through their interactions with service providers. In a study examining public home care service delivery (Malacrida, 2009), women with disabilities reported feeling as though they were not *real* adults capable of responsibilities. They also felt as though they were not seen as gendered or *real* women with the possibility of being in caring and intimate relationships.

The marginalized position of women with ASD may be further deepened by the dearth of research focused on their specific needs. Understanding and addressing barriers and patterns in service access disparities, with explicit attention paid to the role of each

person's individual and social ecology, is an integral component to providing quality care to women with ASD.

Current Project

Women with ASD represent a unique population with diverse service needs; however, the research to date is catered to an understanding of the service needs and barriers to care for young males with ASD. These disparities raise important questions regarding the adequacy of services for women with ASD based largely on information garnered from male populations. Using a mixed methods paradigm, the current project explored the service experiences of women with ASD.

Theoretical orientation. The current project based its theoretical foundation in an ecological conceptual framework and postcolonial-feminist perspective. The ecological model, as first introduced by Bronfenbrenner (1979), stresses dynamic systems of relationships that interact to shape an individual's environment and development. The model uses a framework of various levels of interaction across systems, including the microsystem (family), mesosystem (community and peers), exosystem (social and governmental institutions and cultures), and macrosystem (global influences and ideologies; Bronfenbrenner, 1979). Based on the ecological model, individuals' service utilization is predicted by what is identified as the individual and population's needs as influenced by multiple social, cultural, and environmental levels (Green & Kreuter, 1991; Green, Richard, & Potvin, 1996). This perspective has been used as a theoretical foundation informing the Canadian health promotion framework (World Health Organization, 1986).

Postcolonial feminism provides a theoretical lens through which issues of social

stigma, discrimination, equity in health, and accessibility in service utilization are examined and incorporated into analysis (Anderson, 2002, 2006). The current research contains several important aims influenced by a post-colonial feminist perspective. First, issues pertaining to service experiences will be identified and addressed directly from the perspective of women with ASD. This will give service providers and policy makers the opportunity to understand what affected individuals, themselves, define as important issues and problems. Second, this project is policy driven in the sense that it aims to generate an accurate account of the service needs of women with ASD, as well as provide recommendations to improve service provision. Third, this research is committed to the examination of how sex/gender, disability, ethnicity and social economic position may influence service experiences for women with ASD.

Project design. In the rapidly evolving political and economic context of service provision, it has been suggested that research should adopt a pragmatic approach (Barbour, 1999). For many researchers, mixed methods are conceptualized as a “powerful third paradigm choice” (Johnson, Onwuegbuzie, & Turner, 2007, p. 129) that provides the most useful and powerful results. Such a method "draws on employing 'what works,' using diverse approaches, giving primacy to the importance of the research problem and question, and valuing both objective and subjective knowledge” (Creswell, Klassen, Plano Clark & Smith, 2011, p. 4). While there is debate about what constitutes a mixed methods approach (Tashakkori & Creswell, 2007), defining characteristics often include: quantitative and qualitative methods within the same project; a research design with clearly specified sequencing and proportion of significance given to the quantitative and

qualitative elements; and pragmatism as the philosophical underpinning for the research (Denscombe, 2008).

Over time, mixed methods research has gradually gained momentum as a viable alternative method of inquiry in health services research (O'Cathain, Murphy, & Nicholl, 2007). The proportion of health service studies classified as mixed methods research doubled from 15% in the mid-1990s to 30% in the early 2000s (O'Cathain et al., 2007). To date, the majority of service studies in the adult ASD population, however, rely solely on quantitative surveys (e.g., Shattuck et al., 2011). A handful of studies have employed qualitative methods to better understand the perspectives of caregivers of adults with ASD (e.g., Hare et al., 2004), but fewer have included adults with ASD (e.g., Baldwin & Costley, 2016).

The current project followed a concurrent mixed methods design (Creswell, 2003). Data collection took place in two stages. The quantitative phase of the project consisted of online survey data from men and women with ASD. The purpose of the quantitative phase was to identify predictors and correlates of elements of service use, unmet needs and barriers to care. The qualitative phase was composed of focus groups with women with ASD centering discussion on their service experiences. An inductive, semantic-level analysis was conducted to identify themes related to service experiences in the broad areas of assessment and diagnosis, physical and mental health care, social skills development and social supports, postsecondary educational and vocational services, and residential supports, as well as any other relevant service domains identified by participants. Semantic-level analyses focus on what participants actually say, rather than on possible underlying meanings to provide a descriptive outline of commonalities of

experiences (Braun & Clarke, 2006; 2013). Integration occurred in a separate deductive, latent-level (i.e., interpreting relationships underlying semantic content; Braun & Clarke, 2006) analysis to understand the (in)congruence between the two studies and to corroborate, elaborate and/or initiate (re)interpretations of phenomena within the project's ecological and post-colonial feminist theoretical frameworks (Rossman & Wilson, 1985). Figure 1.1 depicts the study design. According to Morse's (1991) mixed methods notation system, capitalized or lowercase letters denote priority in analysis and the '+' sign represents a concurrent relationship. In this project, quantitative and qualitative phases were conducted concurrently and carried the same weight and emphasis (quan + qual).

Chapter 2: Comparing the Service Patterns of Women and Men with Autism Spectrum Disorder

Adults with Autism Spectrum Disorder (ASD) are one of the most complex yet underserved clinical populations in Canada (Lunsky et al., 2013; Stoddart et al., 2013). Characterized by impairments in social communication and restricted behavior and interests (American Psychiatric Association, 2013), individuals with ASD often have complicated adaptive, physical and mental health care needs reflected in their disproportionately high use of services across different sectors (Barrett et al., 2015; Hodgetts, Zwaigenbaum, & Nicholas, 2015; Weiss et al., 2018). Despite a significant need for services, many caregivers of children with ASD experience significant difficulty accessing appropriate services for a variety of reasons, including lack of information, unavailability of appropriate services, unaffordability of services and lack of skilled professionals (e.g., Brookman-Frazer et al., 2012; Cassidy, McConkey, Truesdale-Kennedy & Slevin, 2008). Comparatively, fewer studies have considered the experience of ASD in adulthood (e.g., Turcotte et al., 2016; Vogan et al., 2017), and little is known regarding the patterns of service use and unmet service needs of Canadian individuals with ASD, which may differ across the lifespan (Lai & Weiss, 2017).

In the typically developing population, several studies have found that women make greater use of certain health, community, and social services than men, yet often report significantly greater unmet service needs (e.g., Koopmans & Lamers, 2007). However, most large scale quantitative studies have not found significant sex/gender specific patterns of service use among individuals with ASD (e.g., Bromley et al., 2004; Ruble & McGrew, 2007; Shattuck et al., 2011; Zablotsky et al., 2015). A lack of

significant sex/gender differences in overall service patterns in the research to date may reflect more nuanced sex/gender barriers to care, which may remain undetected in large administrative datasets. For instance, in an Australian-wide survey using self-report data from 82 women and 200 men with ASD without an intellectual disability (ID; Baldwin & Costley, 2016), no significant quantitative sex/gender differences in service utilization data emerged; however, qualitative data highlighted the subtle and complex challenges faced by women, including high mental health needs, individualized support needs in postsecondary education and employment settings, and prevalent feelings of social exclusion (Baldwin & Costley, 2016).

In addition to sex/gender related differences, an ecological model (Bronfenbrenner, 1979) posits that individuals' service needs and receipt of services are influenced by the interaction of the individual and population's needs with multiple individual and socio-cultural factors (Green & Kreuter, 1991; Green et al., 1996). In the ASD and broader intellectual/developmental disability (IDD) literature, a variety of factors are known to impact service use and unmet service needs. These include factors at the microsystem (e.g., individual and familial characteristics such as age, ethnicity, physical health status, mental health status, socioeconomic status; e.g., Cidav, Lawer, Marcus, & Mandell, 2013; Shattuck et al., 2012), mesosystem (e.g., community level characteristics such as community size, distance to available services; e.g., Thomas et al., 2007) and exosystem (e.g., systemic factors such as service eligibility criteria, service availability, provider knowledge; e.g., Weiss & Lunsky, 2010) levels.

The large and increasing number of adults with ASD in Canada underscores the importance of identifying successful pathways to care for women and men with ASD

(Stoddart et al., 2013). Examining lifetime service patterns, as compared to time-limited reports (e.g., within the last six months), is an important preliminary step to comprehensively understand this population's service needs and identified barriers to care. Adults with ASD have qualitatively described a waxing-waning pattern of support needs across service sectors in response to varying dimensions of mental health (Griffith et al., 2012), which necessitates a broad lens to capture the full range of experiences.

Current Study

The current study aimed to provide a descriptive analysis of the lifetime service use, unmet service needs, and identified barriers to care of Canadian men and women with ASD. Based on the previous literature review (see Chapter 1), services of focus will include: (1) physical health care; (2) mental health care; (3) social skills supports; (4) postsecondary educational supports; (5) employment supports; and (6) residential supports. Specifically, the current study aimed to address the following research questions:

1. What proportion of women and men with ASD identify using the following services across their lifespan: physical health care²; mental health care; social skills development and support; postsecondary educational supports; employment supports; and residential supports?
2. What proportion of women and men with ASD identify unmet needs across the lifespan in the following service domains: mental health care; social skill supports; postsecondary educational supports; employment supports; and residential supports?

² Current physical health care only was assessed (i.e., in the last 12 months) as specified by the Canadian Autism Spectrum Disorder Alliance (CASDA) survey.

3. What proportion of women and men with ASD identify difficulty obtaining the following services: mental health care; social skills services; postsecondary education supports; employment supports; and residential supports?

A secondary, exploratory aim of the current study was to identify specific micro (i.e., age, ethnicity, physical health conditions, mental health conditions, financial status), meso (i.e., community size) and exo-system (i.e., systemic barriers to care) predictors of these patterns of total service utilization and unmet needs. The current study aimed to address the following exploratory research questions:

1. a) What micro (i.e., sex/gender, age, ID status, education level, physical health conditions, mental health conditions, financial status), meso (i.e., community size) and exo-system (systemic service barriers) factors predict total service use across the lifespan for adults with ASD?
b) Are there significant sex/gender interactions within the above stated model?
2. a) What micro (i.e., sex/gender, age, ID status, education level, physical health conditions, mental health conditions, financial status), meso (i.e., community size) and exo-system (systemic service barriers) factors are predictors of unmet service needs across the lifespan for adults with ASD?
b) Are there significant sex/gender interactions within the above stated model?

Based on the previous review of the ASD service literature (see Chapter 1), the following hypotheses were formulated:

1. It was hypothesized that a greater proportion of women with ASD would report use of mental health treatment and physical health services relative to men. No significant sex/gender differences were expected in the domains of social skills

- services, postsecondary education supports, employment supports, or residential supports.
2. It was hypothesized that a greater proportion of women with ASD would report unmet needs in the domains of mental health treatment and employment supports relative to men with ASD. No significant sex/gender differences were expected in the domains of social skills services, postsecondary education supports, or residential supports.
 3. It was hypothesized that a greater proportion of women than men with ASD would report difficulties obtaining mental health treatment and employment supports. No significant sex/gender differences were expected in the domains of social skills services, postsecondary education supports, or residential supports.

Methods

Participants

Eligibility requirements for the current study were met if participants: 1) were 18 years of age or older; 2) identified as female or male (individuals who identified as transgender or other were not included in the current study); 3) were current residents of Canada; 4) completed the survey independent of others' assistance; and 5) had received a diagnosis of ASD (defined as having a diagnosis of Autism, Asperger Syndrome, Pervasive Developmental Disorder-Not Otherwise Specified, Pervasive Developmental Disorder, or Autism Spectrum Disorder) by a qualified healthcare professional (e.g., medical doctor, psychologist). A total of 22 individuals were excluded from the current study for the following reasons: one individual did not report having received an ASD diagnosis; 10 individuals did not identify as male or female (i.e., identified as transgender

or other); 11 individuals indicated that they received assistance in completing the survey.

The final sample consisted of 141 adults with ASD (49.6% female) ranging in age from 19 to 64 years ($M = 35.74$, $SD = 10.73$). Participants' province of residence was as follows: Ontario (51.8%), British Columbia (11.3%), Quebec (9.9%), Alberta (8.5%), Nova Scotia (7.8%), New Brunswick (5.7%), Saskatchewan (2.1%), Prince Edward Island (1.4%), Manitoba (0.7%), and Newfoundland (0.7%). The majority (90.8%) of participants identified as white/Caucasian. Approximately 71.2% of participants reported that they were employed in a paid position or attending school at the time of survey completion. Most participants (56.7%) lived independently in their own house or apartment, 35.5% lived at a family member's place of residence, and 7.8% lived in other residential settings (e.g., alternative group home). There were no significant sex/gender differences according to province of residence, ethnicity, employment status, or place of residence (all p 's $>.05$).

Measures

Microsystem variables.

Demographics. Participants were asked their identified sex/gender (female or male), age, and highest level of education attained (high school level certificate or less; college level diploma; undergraduate degree; graduate/professional degree).

Intellectual disability status. Participants were asked the following question: "Has a doctor or health professional ever told you that you have: Intellectual Disability, Developmental Disability, Developmental Delay?" with responses coded as Yes / No/ Not sure. "Not sure" responses were recoded to "No".

Mental and physical health status. Participants were asked a set of questions

adapted from Gurney, McPheeters and Davis (2006) to assess for common physical and mental health conditions across their lifespan. An overall physical health problem score was calculated based on total endorsements of lifetime experience of 11 possible medical problems (e.g., gastrointestinal problems; hearing problems, vision problems, bone, joint and muscle problems). Responses were dichotomized into those participants with and without at least one comorbid medical condition. Similarly, mental health conditions were dichotomized into the presence/absence of at least one comorbid psychiatric condition based on participant report of lifetime psychiatric diagnoses of any of the following diagnoses: anxiety disorder, ADHD/ADD, depression, obsessive-compulsive disorder, schizophrenia/psychotic disorder or other). Past surveys in the IDD literature have used similar dichotomous reporting of co-occurring medical and mental conditions (Gurney et al., 2006; Montes & Halterman, 2008).

Financial status. Based on the British Families and Children’s Study (Lyon, Tait & D’Souza, 2005), participants were asked the following question regarding their financial status as an index of socioeconomic status: “Which of the phrases best describes how you are managing financially these days” and were provided with the following six response options: (a) *I manage very well* (b) *I manage quite well* (c) *I get by alright* (d) *I don’t manage very well* (e) *I have some financial difficulties* and (f) *I am in deep financial trouble*. Responses were dichotomized to reflect financial difficulty (response options *d-f*) and no financial difficulty (response options *a-c*).

Mesosystem variable.

Community size. Participants were asked the following question regarding the size of their communities: “What is the best way to describe the size of your

community?” and were provided with the following four response options: (a) *I live in a remote area of the country* (b) *I live in a rural area of the country* (c) *I live in a suburban area of the country* and (d) *I live in an urban area of the country*. Based on the distribution of responses, community size categories were recoded to remote/rural, suburban, or urban.

Exosystem factors.

Systemic barriers. Participants were asked if they experienced any of the following systemic barriers to service use, as part of a checklist of 10 reasons for not accessing services adapted from Douma, Dekker, De Ruiter, Verhulst, and Koot (2006): *cannot afford services, negative experiences with professionals in the past, not enough resources – on a waitlist, lack of trained professionals, diagnosis does not qualify for services; too young; too old; services are too far; services are not available in the right language; deemed ineligible for a service even if you have a diagnosis that should qualify*. A total score of systemic barriers was computed by summing the number of endorsed individual barriers.

Outcome variables.

Service use. Participants were asked the following questions regarding their service use: “Please select any supports or services that you are currently or recently receiving (in the last 6 months), have received in the past only (at least 7 months ago or longer), or have never received” and were provided with a list of 21 services, including the following five services of focus for the current study: mental health care, social skills services, postsecondary educational supports, employment supports, and residential supports. Individual service use was dichotomized into used/not used. Medical health

service use was assessed with the following question: “Have you accessed a family doctor in the last 12 months?” Lifetime service use was examined at the individual service level, in addition to total service use. Total scores for lifetime service use were calculated by summing frequency counts across the six individual services for a cumulative total score of services used.

Unmet service needs. Participants were asked the following questions regarding their lifespan unmet service needs: “Which of the following services have you been unable to receive (ever), which you would like to have received?” and were provided with a list of 21 services, including the five services of focus for this study. Unmet service needs were examined at the individual service level, in addition to total unmet needs. A total score of unmet service needs was calculated by summing frequency counts across the five individual services for a cumulative total score of services used. Unmet need with respect to lifetime medical health service use was not included in the CASDA survey.

Difficult to obtain services. To assess barriers at the individual service level, participants were asked, “Have you ever had difficulty obtaining any of the following services?” and were provided with a list of 21 services, including the five services of focus for the current study. Difficult to obtain services were examined at the individual service level, in addition to the total number of endorsed services.

Procedure

Recruitment occurred between April to July 2014. The online survey was disseminated by 60 CASDA member organizations, which represent individuals with ASD and their families in all Canadian provinces and territories, via newsletters,

websites, email, and social media (e.g., Twitter, Facebook) campaigns. Following the first month of recruitment, CASDA organizations made direct phone calls to reach communities with lower response rates (see Lai & Weiss, 2017 for further information). The survey was available in French and English. Ethics approval was obtained from the York University Research Ethics Committee and participants provided informed consent prior to completing the survey.

Data Analysis

Data screening and assumption testing. Frequency and descriptive analyses were used to detect missing data. Data were screened for univariate and multivariate outliers. Data were also checked for assumptions of multivariate analyses including normality, linearity, homoscedasticity, and multicollinearity. Given the distribution of the unmet service need variable (see below), assumptions specific to the Poisson regression analyses were also tested, including that the distribution of counts followed a Poisson distribution and equidispersion.

Descriptive analyses. Frequency and descriptive analyses by sex/gender were conducted for all micro, meso, and exo system variables using *t*-tests and chi-square analyses.

Preliminary analyses. The relationships between all predictor variables apart from sex/gender (described above) were examined using *t*-tests, one-way ANOVA, point biserial correlations, chi-square analyses, and Mann Whitney *U* tests.

Main results. For all analyses, effect sizes were calculated with Cohen's *d* or η^2 when comparing parametric group differences, phi (Φ) when comparing categorical data, and $r (z/\sqrt{N})$ when using nonparametric tests (Fritz, Morris, & Richler, 2012). To

contextualize significant findings, bivariate relationships between service variables and micro, meso, and exosystem variables were explored using independent sample *t*-tests and chi-square analyses.

Research question 1: Service use. Chi square tests were used to compare sex/gender differences in individual lifespan service use domains. Independent sample *t*-tests were used to compare sex/gender differences in total cumulative lifespan service use rates.

Research question 2: Unmet service needs. Chi square tests were used to compare sex/gender differences in individual lifespan unmet service needs domains. Given the non-normal distribution, a Mann Whitney *U*-test was used to compare sex/gender differences in total cumulative lifespan unmet service needs.

Research question 3: Difficult to obtain services. Chi square tests were used to compare sex/gender differences in individual services endorsed as difficult to obtain. A Mann Whitney *U*-test was used to compare sex/gender differences in the cumulative total of services endorsed as difficult to obtain due to the variable's non-normal distribution.

Exploratory research questions.

Exploratory research question 1a): Predictors of total service use. As the total service use variable followed a normal distribution, a hierarchical linear regression analysis was undertaken. Initially, each micro, meso and exo system variable was entered into a univariate model with total service use as the outcome variable. Age and total systemic barriers were centered prior to entry as a predictor variable. The following categorical and ordinal variables were dummy coded: sex/gender (men as reference group), education (high school as reference group), ID status (no ID as reference group),

financial status (no financial difficulty as reference group), medical comorbidity (no comorbidity as reference group), and psychiatric comorbidity (no comorbidity as reference group). Next, to identify the most parsimonious combination of variables³ that would explain total service use and potential sex/gender interactions, all variables significant at $p < .10$ in univariate simple regression analyses were then entered into a hierarchical regression. The hierarchical regression was composed of two steps with variables entered in the following order: 1) all variables significant at $p < .10$ in univariate simple regression analyses; 2) sex/gender interaction terms calculated for predictors significant at $p < .05$ in the adjusted multivariate model in Step 1.

Exploratory research question 2a): Predictors of unmet service needs. Due to the positively skewed distribution of counts for the unmet service needs variable, Poisson regression was identified as an appropriate method of analysis (Hardin & Hilbe, 2007). In Poisson regression, the observed scores are counts and the predicted scores are the natural logarithms of the counts. The Poisson distribution has a single parameter that describes both the mean and variance, known as equidispersion. Linear regression is not appropriate for such data as the linear model might lead to prediction of negative counts and the errors will not be normally distributed (Cameron & Trivedi, 2013). Similar to the

³ Various variable selection strategies aimed at achieving a balance between including informative variables and model parsimony were considered. In the current study, the minimum acceptable sample size requirement for multiple regression analyses ($104 + n$ predictors; Tabachnick & Fidell, 2007) was met, however, the risk related to the high number of parameters (nine predictor variables with multiple levels and eight potential interaction terms) relative to the number of observations ($n = 140$ respondents with complete data) was high (Field, 2009). Variable selection processes based on significant bivariate analyses are common in the IDD service use literature (e.g., Pickard & Ingersoll, 2016; Lai & Weiss, 2017; White, Scahill, Klin, Koenig, & Volkmar, 2007); however, overfitting a model resulting in biased prediction is recognized as an associated risk (Murtaugh, 2009). Results from the current exploratory study were accordingly interpreted with caution.

above stated analyses for the total service use variable, each micro, meso, and exo system variable was first entered into a univariate model with total unmet service needs as the outcome variable. Variables significant at $p < .10$ in univariate regression analyses were then entered into a two-step hierarchical regression with the second step inclusive of sex/gender interaction terms calculated for significant predictors significant at $p < .05$ in the first step. Each model was tested for violations of equidispersion by examining the Chi-square value relative to the residual degrees of freedom.

Results

Data Screening and Assumption Testing

Missing data. Data were complete for all study variables with the exception of highest level of education attained (99.3% complete; $n = 140$ complete). All analyses were conducted listwise so as to only include participants with complete data.

Normality. To examine normality for all continuous variables, box plots and histograms were examined, and skewness and kurtosis values were converted to z scores and then compared to critical values on the z distribution ($p < .001$, critical $z = 3.29$). Totals of unmet service needs and difficult to obtain services were positively skewed, all other continuous variables met this assumption. Non-parametric bivariate tests and multivariate models based on the Poisson distribution were used when analyzing these two variables.

Univariate and multivariate outliers. The data were examined for univariate outliers by visually inspecting histograms and boxplots and calculating z -scores. Totals of services used and unmet service needs each had one univariate outlier, however, these cases were retained for further analyses since they were within the range of possible

values and their z -scores did not exceed the critical value ($p < .001$, critical $z = 3.29$). Multivariate outliers were investigated using Cook's Distance, Mahalanobis Distance, and Leverage values. No cases were identified as influential outliers on the regression models.

Multicollinearity. In analysis of multicollinearity, multivariate regression analyses had neither Variance Inflation Factors over 10 nor Condition Indices greater than 30 with variance proportions greater than .50 on two different variables for a given dimension (Tabachnick & Fidell, 2007).

Regression assumptions. Bivariate scatterplots were visually inspected to test for linearity and homoscedacity of the regression model for the total service use variable and linearity of the unmet service need regression model; these assumptions were met. The independence of errors assumption was tested with the Durbin-Watson test for the total service use model; this assumption was also met.

Poisson regression specific assumptions. A one sample Kolmogorov-Smirnov goodness of fit test was run to test whether the distribution of the unmet service need variable followed that of a Poisson distribution; this assumption was met, $z = .32$, $p = 1.00$. The mean and variance of the unmet service need variable also met the assumption of equidispersion ($M = 1.26$, $\sigma^2 = 1.29$).

Descriptive Analyses

Microsystem variables. Distributions of participants' responses for categorical microsystem variables (education, ID status, and financial status) by sex/gender are shown in Table 2.1; age, a continuous variable, is shown in Table 2.2. As indicated above, participants ranged in age from 19 to 64 years. Most participants indicated that

they had not received a diagnosis of ID and a large proportion reported having graduated from college or a higher education level. The majority of participants indicated that they were not experiencing financial difficulties. Overall, comorbid health conditions were common.

There were no significant sex/gender differences with respect to age, ID status, or education (see Table 2.1). However, a significantly greater proportion of women identified experiencing financial difficulty as compared to men (see Table 2.1). Additionally, a significantly greater proportion of women reported at least one medical comorbidity and/or at least one psychiatric comorbidity as compared to men (see Table 2.1).

Mesosystem variable. As shown in Table 2.1, a minority of participants reported their community size as remote/rural. Women and men did not significantly differ in terms of their community size.

Exosystem variable. As shown in Table 2.2, participants reported between 0 and 10 barriers to service. Women reported significantly more barriers relative to men.

Preliminary Analyses

Relationships among microsystem variables. Table 2.3 presents correlations among microsystem variables apart from sex/gender. Participants' age significantly differed by education, $F(3, 136) = 8.42, p < .001, \eta^2 = .16$, with post hoc Tukey tests indicating that individuals with high school level certificates as their highest level of education achieved were significantly younger than those with college level diplomas ($p = .001$), undergraduate degrees ($p = .004$), and graduate/professional degrees ($p < .001$). Individuals with a medical or a psychiatric comorbidity were more likely to experience

financial difficulty compared to those without a medical comorbidity (6.9%), $\chi^2(1, N = 141) = 13.55, p < .001, \Phi = .31$, or psychiatric comorbidity (13.8%), $\chi^2(1, N = 141) = 7.92, p = .005, \Phi = .24$. Finally, there was a significant relationship between medical and psychiatric comorbidities, $\chi^2(1, N = 141) = 13.15, p < .001, \Phi = .31$.

Relationships between microsystem and mesosystem variables. There were no significant relationships between any microsystem variable and community size (all p 's $> .05$).

Relationships between microsystem and exosystem variables. The number of systemic barriers did not differ by age, education, or ID status (all p 's $> .05$). Individuals with a psychiatric comorbidity reported a greater number of barriers ($M = 3.42, SD = 2.30$) than individuals without a psychiatric comorbidity ($M = 1.79, SD = 1.97$), $t(139) = 3.49, p = .001, d = 0.76$. Relatedly, individuals with a medical comorbidity reported significantly more service barriers ($M = 3.38, SD = 2.32$) than individuals without a medical comorbidity ($M = 1.97, SD = 2.01$), $t(139) = 2.99, p = .003, d = 0.65$. Finally, those reporting financial difficulty endorsed more barriers ($M = 3.94, SD = 2.18$) than those without financial difficulty ($M = 2.60, SD = 2.28$), $t(139) = 3.41, p = .001, d = 0.60$.

Relationship between mesosystem and exosystem variables. A one-way ANOVA revealed no significant differences in service barriers by community size, $F(2, 138) = 0.62, p = .54, \eta^2 = .01$.

Main Results

Research question 1: Service use. Participants used between zero and six services, with a median of three services ($M = 2.95, SD = 1.49$). With respect to the total number of services used, there was no significant difference between women ($M = 3.03,$

$SD = 1.60$) and men ($M = 2.87, SD = 1.38$), $t(140) = 0.62, p = .54, d = 0.09$. The most commonly used services were family physicians, followed by postsecondary educational supports and mental health care. Table 2.4 presents the percentages of participants who used each individual service by sex/gender. There were no significant sex/gender differences across individual services and supports (all p 's $> .05$), with the exception of mental health services. A greater proportion of women reported using mental health services as compared to men.

To contextualize mental health service use, bivariate relationships among service use and micro, meso and exosystem factors were further explored. In addition to sex/gender, mental health service use was significantly associated with one microsystem (psychiatric comorbidity) and one exosystem factor (service barriers; see Table 2.5). Specifically, individuals were more likely to have a psychiatric comorbidity and endorsed a greater number of service barriers compared to those who did not use mental health services.

Research question 2: Unmet service needs. Overall, participants identified between zero and five unmet service needs ($M = 1.25, SD = 1.13; Mdn = 1.0$). As shown in Table 2.6, residential supports, social skills services, and employment supports were the most frequently reported unmet service needs. There were no significant sex/gender differences in participants' unmet service needs by individual services (see Table 2.6, all p 's $> .05$). Additionally, there was no significant difference in the total number of unmet service needs between women ($M = 1.40, SD = 1.22; Mdn = 1.00$) and men ($M = 1.11, SD = 1.04; Mdn = 1.00$), $z = -1.28, p = .20, r = -.11$.

Research question 3: Difficult to obtain services. Participants reported experiencing difficulty obtaining between zero and five services ($M = 1.65$, $SD = 1.67$; $Mdn = 1.00$). No significant difference was found in the total number of services that were endorsed as difficult to obtain between women ($M = 1.81$, $SD = 1.62$; $Mdn = 1.50$) and men ($M = 1.49$, $SD = 1.71$; $Mdn = 1.00$), $z = -1.42$, $p = .16$, $r = -.12$. Overall, mental health services, residential supports, and employment supports were the services most frequently identified as difficult to obtain. Table 2.7 presents data for individual services that were endorsed as difficult to obtain by sex/gender. A significantly greater proportion of women indicated that they experienced difficulty obtaining mental health services as compared to men. Similarly, a significantly greater proportion of women indicated that they experienced difficulty obtaining residential supports as compared to men.

To better understand these significant findings, bivariate associations of micro, meso, and exosystem factors and difficulties obtaining mental health and residential supports were explored. As seen in Table 2.8, individuals who indicated they experienced difficulty obtaining mental health services were significantly older and more likely to have a psychiatric and/or a medical comorbidity than those who did not endorse this difficulty. Those who identified difficulty obtaining mental health services similarly endorsed a greater number of service barriers and were more likely to experience financial difficulty. With respect to residential supports, individuals who experienced difficulty obtaining this service endorsed a greater number of service barriers and were more likely to experience financial difficulty (see Table 2.9).

Exploratory Research Questions

Exploratory research question 1: Service use. In the simple regression models, associations of total service with two microsystem variables (age and psychiatric comorbidity) were found to be significant at $p < .10$ (see Table 2.10). To identify the adjusted influence of these variables and explore possible sex/gender moderation effects, a hierarchical multiple regression analysis was conducted consisting of two blocks entered in the following order: 1) sex/gender, age, and psychiatric comorbidity; 2) the product of sex/gender and any significant predictor at $p < .05$ in Step 1.

The overall model at Step 1 was significant. Age and psychiatric comorbidity both emerged as significant predictors of service use (see Table 2.11, Step 1). In Step 2, no sex/gender interaction effect was significant (see Table 2.11), indicating that sex/gender does not moderate the relationships between age and service use, or psychiatric comorbidity and service use. Psychiatric comorbidity emerged as the sole significant predictor in Step 2 and the added interaction terms did not significantly improve the model, $F_{\text{change}}(2, 135) = 2.31, p = .10, R^2_{\text{change}} = .03$.

Exploratory research question 2: Unmet service needs. Univariate regression analyses of unmet service needs are presented Table 2.12. Age, financial difficulty, medical comorbidity, and psychiatric comorbidity were significant microsystem predictors of unmet service needs at $p < .10$. Additionally, community size was a significant mesosystem predictor and total service barriers was a significant exosystem predictor of unmet service needs in the simple regression analyses. A two-step Poisson regression analysis was conducted to identify the adjusted influence of these variables and explore possible sex/gender moderation effects. The blocks were entered in the following order: 1) sex/gender, age, financial difficulty, medical comorbidity, psychiatric

comorbidity, community size, service barriers; 2) the product of sex/gender and any significant predictor at $p < .05$ in Step 1.

In Step 1, the model demonstrated appropriate fit of a Poisson distribution, $\chi^2(136, N = 141) = 116.58, p = .83$. As seen in Table 2.13 (Step 1), financial difficulty and systemic barriers emerged as significant predictors of unmet service needs at $p < .05$. The overall model at Step 1 was significant. In Step 2, the model similarly demonstrated appropriate fit of a Poisson distribution, $\chi^2(130, N = 141) = 116.93, p = .79$. No sex/gender interaction effect emerged as significant at $p < .05$ (see Table 2.13, Step 2) and service barriers emerged as the sole significant predictor of unmet service needs at $p < .05$.

Discussion

This is the largest study to date providing a descriptive analysis of service use, unmet service needs, and barriers to care from the perspectives of Canadian adults with ASD. Few significant sex/gender differences emerged overall, with the exception of mental health and residential services. Applying the framework of Bronfenbrenner's (1979) ecological model, however, a number of significant associations between service outcome variables and micro, meso, and exo system factors were found. Taken together, these findings highlight the individual-contextual dynamics of this population's service experiences. A better understanding of these service patterns can help to inform policy to improve service provision for adults with ASD.

Descriptive Results

A significant proportion of both women and men (79%) reported a co-occurring medical and/or psychiatric condition, which underscores the complex care needs of adults

with ASD. Comorbidity among adults with ASD vary widely, with estimated rates ranging from 25% to over 75% dependent upon study, measure, and/or informant (Buck et al., 2014; Croen et al., 2015; Joshi et al., 2013; Levy & Perry, 2011; Weiss et al., 2018). It is interesting to note the greater proportions of women with psychiatric and/or medical conditions as compared to men. Similar sex/gender differences have emerged with respect to co-occurring medical conditions in the adult ASD literature (Croen et al., 2015; Fortuna et al., 2016), while findings related to psychiatric conditions are more mixed (Croen et al., 2015; Lai et al., 2011; Maddox, Trubanova, & White, 2017). It is important for future research to identify the predisposing and precipitating factors that may underlie an increased risk for women with ASD.

In addition to co-occurring medical and psychiatric conditions, a greater proportion of women in the current study reported financial difficulty and endorsed a greater number of systemic barriers to care than men. Linked to varied socio-political factors, Canadian women, in general, are consistently shown to earn less than their male peers and are at a significantly higher risk of living in poverty (Townson, 2000). Accordingly, it is noteworthy in the current study that, despite similar employment statuses, women with ASD reported greater financial difficulty than men. The finding that women with ASD endorsed a greater number of systemic barriers (e.g., *not enough resources; negative experiences with professionals in the past; lack of trained professionals*) may reflect the gendered inequality in evidence-based treatment options for women in the general population. Women have historically been excluded from clinical trials, resulting in inadequate provider knowledge and service provision (Vidaver

et al., 2000). These systemic barriers may be especially pronounced for women with ASD, a subsample of women that has been neglected in clinical research to date.

The current study highlighted the interrelationships between sex/gender, comorbid physical and mental health conditions, financial difficulty, and systemic barriers to care. The well-documented female preponderance of multimorbidity in the general population (see Violan et al., 2014 for review) is associated with a host of microsystem (e.g., biological vulnerabilities, health seeking behavior, financial status; Galdas, Cheater, & Marshall, 2005), mesosystem (e.g., community size; Bushy, 1990) and exosystem (e.g., systemic barriers to care, such as provider knowledge; Sherr & Lawrence, 2000) factors. In the current study, the significant correlations among these variables emphasize the notion that a woman's health status does not present within a vacuum, as well as the important role that individual-contextual dynamics should play when modeling service needs and use.

Research Question 1: Service Use

Multiple service use was common among adults with ASD in the current study. Women with ASD demonstrated equally high rates to those of their male counterparts with respect to overall service use. Contrary to the hypothesis, there was no significant sex/gender difference in physical health services (i.e., the likelihood of having seen a family physician within the last 12 months). These physical health service results differ from what is reported among typically developing men and women (e.g., Bertakis et al., 2000); however, Tint et al. (2017) similarly found no significant sex/gender differences in family physician visits over a 12- to 18-month follow-up period among adolescents and adults with ASD. Overall, these data suggest that women and men with ASD alike may

require services that span multiple sectors and speak to the importance of integrated service planning and treatment provision.

As hypothesized, a greater proportion of women (75.7%) reported mental health service use compared to men (50.7%). These results follow what is commonly found in the general population (e.g., Rhodes et al., 2002) as well as recent parent-report findings in the ASD literature (Tint et al., 2017). Greater mental health service use may simply relate to greater clinical need, as women in the current study were more likely to report a comorbid psychiatric diagnosis than men. However, sociological perspectives associate these mental health service disparities to conceptions of gender and gender practices (Rosenfield & Mouzon, 2013). Specifically, in Western cultures, men are said to be socialized according to principles of masculinity where stoicism, strength, and emotional suppression are idealized and consequently associated with negative attitudes towards seeking psychological help (Blazina & Watkins, 1996). Further, others have argued that gender stereotypes are internalized by referring physicians, who tend to interpret symptoms presented by women differently than those presented by men (Ashton, 1991; Rosenfield & Mouzon, 2013). While men's presenting concerns are traditionally seen as somatic, women's are viewed as psychological in nature, leading to over diagnosis of psychiatric disorders and, in turn, increased mental health service use.

Questions remain whether sex/gender differences in mental health service use represent unmet (and possibly under reported) need for care among men with ASD and/or inappropriate service overuse and ineffective care provision for women with ASD. In support of the latter theory, there remains a lack of an evidence base for treating women with ASD and co-occurring mental health problems, which could lead to ineffective

service provision. Women with IDD, including ASD, are often excluded from the larger field of women's mental health research (Taggart et al., 2008), and in the limited treatment research on ASD and mental health, sex/gender differences are rarely examined directly (Thompson et al., 2003; Watkins et al., 2014). It is important for future research on the mental health of adults with ASD to include sex/gender analyses.

Research Question 2: Unmet Service Needs

It was hypothesized that a greater proportion of women with ASD would report unmet needs in the domains of mental health treatment and employment supports relative to men with ASD; however, no significant sex/gender differences were found in the total number of unmet service needs, or with respect to individual services. Overall, participants identified a relatively low number of unmet needs (median = 1 unmet service need) compared to past research (Turcotte et al., 2016; Vogan et al. 2017). This surprising finding may relate to a methodological limitation of the current survey. Specifically, the unmet service need variable was worded as such: *Which of the following services and supports have you been unable to receive (ever), which you would have liked to receive?* It follows that participants' service receipt, in and of itself, may not equate to service need fulfillment. That is, service utilization rates may not reflect an optimal measure of unmet needs as no information is provided regarding the appropriateness (e.g., timing relative to need) and/or adequacy (e.g., quality) of the services used (Thiede, Akweongo, McIntyre, & Mooney, 2007). Unfortunately, the current data does not allow for further disentanglement of adults' service access needs, though from the policy perspective of allocating resources relative to need, this topic merits further study.

Regardless of methodological limitations, it is telling that residential services and

employment supports were among the most frequently reported unmet service needs for both men and women. Past research has found that few adults with ASD are employed full time and those who are employed are often underpaid (Howlin & Moss, 2012). Based on a US nationally representative survey (Roux et al., 2013), only one-half of young adults with ASD had ever worked for pay outside the home since leaving high school, the lowest rate among disability comparison groups, including those with ID, learning disabilities, emotional problems, and speech-language impairments. On average, young adults with ASD earned \$8.10/hour, which was also significantly lower in comparison to other disability groups. Likewise, a minority of adults with ASD have been shown to live independently and many rely on their families through adulthood (Howlin & Moss, 2012; Shattuck et al., 2012). In fact, compared with young adults with other disability types, those with ASD are more likely to live with a parent or guardian and the least likely to have ever lived independently since leaving high school (Anderson et al., 2014). Autism Spectrum Disorder is considered a life-long neurodevelopmental disorder (APA, 2013) and, while the service needs of affected individuals change across the lifespan (Lai & Weiss, 2017; Turcotte et al., 2016), the service system appears ill equipped to meet the needs of adults with ASD as these adult centric service needs remain significantly underserved (Gerhardt & Lainer, 2010).

Approximately 40% of the sample endorsed unmet social skills programming needs. In a Canadian sample of parents of individuals with ASD, Lai and Weiss (2017) found that social skills programming was identified as a high priority service need across the lifespan. Impaired social skills are often considered the most significant challenge for individuals with ASD, impacting the ability to develop and maintain meaningful

relationships (Reichow & Volkmar, 2010). Despite this significant need, few evidence-based social skills interventions exist for the growing population of adults with ASD (White et al., 2007).

Research Question 3: Difficult to Obtain Services

Almost 40% of the sample reported difficulty obtaining mental health services in the current study. Research has substantiated a need for increased clinical training by psychology students, medical students and psychiatry residents to provide effective healthcare, including mental health care, to individuals with IDD in Canada (Burge et al., 2008; Lunsky & Bradley, 2001; Weiss et al., 2010). Difficulties accessing mental health services may also reflect the fragmented system of care in Ontario, where two different ministries regulate service provision for individuals with ASD and those with mental health problems. The Ministry of Community and Social Services fund certain services for individuals with ASD (e.g., in home and out-of-home respite care, day programming, residential services), while the Ministry of Health and Long-Term Care funds the assessment and treatment of mental health problems (e.g., community mental health care). The two sectors are not always well connected and can be very difficult for individuals to navigate (York Support Services Network, 2008).

In support of the stated hypothesis, a greater proportion of women reported difficulties obtaining mental health supports than men. This may relate to sex/gender differences in relative need of mental health services, and relatedly, occasion for encountering difficulties while obtaining services. Women's pronounced difficulty accessing mental health services may also relate to sex/gender differences in systemic factors. Specifically, women were more likely to report financial difficulty and a greater

number of service access barriers than men. Past research has shown marked socioeconomic status gradients in mental health care in Ontario (Steele, Glazier, & Lin, 2006). Administrative data have shown higher rates of specialty mental health services use in higher-income neighbourhoods (Tataryn et al. 1994; Steele et al., 2006). Further research is needed to discern if these service access inequities among women with ASD are driven by individual factors (e.g., mental health literacy) or provider-driven variables (e.g., likelihood of referral for speciality mental healthcare).

An interplay of individual and contextual factors may also elevate women's risk for encountering mental health service access difficulties. Women with ASD may face difficulties accessing appropriate mental health care related to sex/gendered presentations of ASD symptoms and/or co-occurring mental health difficulties. Recent qualitative work has described the challenges women with ASD encounter when accessing mental health supports due to their ability to compensate for, or mask, their ASD-related social communication difficulties, which can result in health care professionals' perceived dismissal or disbelief of their concerns due to these unique presentations (Bargiela et al., 2016; Tierney et al., 2016). Likewise, sex/gender differences in symptom profiles, frequency, duration, and coping styles of mental health difficulties may further impact service access difficulties (Parker & Brotchie, 2010). For instance, women are more likely to report somatic symptoms of depression (e.g., changes in appetite) while men more often report cognitive symptoms (e.g., concentration difficulties; Piccinelli & Wilkinson, 2000; Wang & Gorenstein, 2015). With these potential sex/gender differences in mind, further work is needed to build health providers' capacity to identify and effectively treat mental health problems in women with ASD.

Contrary to hypothesis, a greater proportion of women reported difficulty obtaining residential supports than men. Similar to mental health services, this may reflect sex/gender differences in financial difficulty and service barriers. A small Canadian parent report study highlighted a need for gender specific residential supports for adults with IDD (Weeks et al., 2009); however, there is very little research on residential services for adults with ASD (Anderson et al., 2014; Hewitt et al., 2017). Adequate housing choices and supports for individuals with ASD are essential components of community participation and wellbeing and remain an important systemic policy consideration (Hewitt et al., 2017).

Exploratory Research Question 1: Service Use

Age and psychiatric comorbidity, two microsystem factors, emerged as significant predictors of service use at the bivariate level as well as in the adjusted regression model. Older age predicted less service use, a finding that corresponds to past research (Lai & Weiss, 2017; Shattuck et al., 2011; Turcotte et al., 2016), and is often attributed to the scarcity of supports for individuals once they have exited the school system. However, as the current study assessed lifetime service use, this age related finding might also correspond to a cohort effect. Perhaps related to changes in diagnostic criteria and greater awareness of ASD, increased prevalence rates of ASD in recent years have resulted in increased service availability (Hansen, Schendel, & Parner, 2015). A substantial number of adults are beginning to come forward for first ASD diagnosis in adulthood (Mukaetova-Ladinska, Perry, Barron, & Povey, 2012; Povey, Mills, & Gomez de la Cuesta, 2012), and it may follow that this subgroup would report less lifetimes service use than those who received diagnoses in childhood.

The current finding that having a diagnosed comorbid psychiatric disorder predicted greater service use, was not surprising given that mental health services was one of the types of services included in the overall service count. This finding also corresponds to past research involving the service of youth with ASD transitioning to adulthood over the last 12 months (Taylor & Henninger, 2015) but differs from other research looking at the service use of individuals with ASD reporting over a recent 6-month period (Lai & Weiss, 2017) and that of children with ASD ages 6 to 17 over a recent 6-month period (Zablotsky et al., 2015). Neither Lai and Weiss (2017) nor Zablotsky et al. (2015) reported psychiatric comorbidity as a significant predictor of service use. The current study, however, focused on lifetime service use, and it is conceivable that those with a psychiatric diagnosis and receiving mental health services may be better connected with a greater net total of services for adults over time.

It is interesting to note the lack of significant mesosystem and macrosystem factors when modeling service use. Additionally, no evidence was found for sex/gender interactions within the adjusted model. These null findings should be interpreted with caution due to the relatively small sample size and limited ways of measuring these variables. With respect to sex/gender interactions, there is limited evidence to date of differential patterns of service use among women with ASD; however, qualitative work has highlighted subtle sex/gendered service barriers (e.g., difficulties accessing services due to atypical clinical presentations; Baldwin & Costley, 2016), which may remain undetected in quantitative analyses of overall service use.

Exploratory Research Question 2: Unmet Service Needs

Consistent with extant studies (e.g., Lai & Weiss, 2017; Taylor et al., 2015;

Zablotsky et al., 2015), several microsystem (age, financial difficulty, medical comorbidity, psychiatric comorbidity), mesosystem (community size), and exosystem factors (service barriers) emerged as significant predictors of unmet service needs at the bivariate level. The sizes of these relationships, however, were small and ceased to be significant when entered into an adjusted model, save for financial difficulty and service barriers. Multiple studies have highlighted how individuals with IDD face significant barriers accessing services (Lai & Weiss, 2017; Vogan et al., 2017; Weiss & Lunskey, 2010). Services for individuals with ASD are also costly and may not be sufficiently covered within the publicly funded service system. This may be especially true for adults who have aged out of the school system and children's services, making financial difficulty a significant contributor to unmet service needs.

Bivariate correlations and predictors of service use were substantially different from those that were associated with unmet needs. This highlights the usefulness of considering both aspects of service experiences of adults with ASD. In contrast to service use, unmet service needs appear to be driven by financial and systemic factors as compared to demographic and clinical characteristics; however, no sex/gender interaction effect was similarly apparent for unmet service needs. Overall, findings emphasize service access challenges and the need to make services more accessible and affordable for all adults with ASD. This is particularly important as past research has shown adults with ASD may become increasingly distressed when service needs remain unmet (Vogan et al., 2017). Future work is needed to identify effective methods of assisting individuals with ASD to navigate an often fragmented and under resourced service system.

Study Strengths, Limitations, and Future Directions

This study contributes to the growing body of research on the experiences of women with ASD. It is well established that women in the general population have distinctive service patterns (Green & Pope, 1999; Ladwig, Marten-Mittag, Formanek, & Dammann, 2000; Rhodes et al., 2002) and the current study highlights those of women with ASD, particularly in the areas of mental health and residential supports. As more information regarding potential sex/gender differences in ASD clinical presentation emerges, it is important to continue to clarify the service experiences of women with ASD to ensure the provision of appropriate supports.

The current study represents the largest Canadian self-report sample of service use, unmet needs, and barriers to care of adults with ASD. Parent-report and administrative data studies have examined patterns of adults' service use (Lai & Weiss, 2017; Taylor & Henninger, 2015; Tint et al., 2017; Turcotte et al., 2016) but far fewer have reported on the perspectives of affected individuals. Not all adults with ASD live with caregivers and it is necessary to understand the experiences of those who may access services independently. Moreover, the service needs of adults is recognized as a priority research area by various stakeholders within the ASD community, and adults with ASD have advocated for their own involvement in such research (Pellicano et al., 2014).

Results from this study should be interpreted with caution due to several limitations. First, service use information consisted of self-report data and may be susceptible to recall bias. Future research combining administrative data with the personal experiences of adults with ASD is needed to achieve a comprehensive understanding of this population's service experiences. While the current sample is large relative to extant research, replication with larger sample sizes is warranted. Future work

with larger samples would enable more detailed analyses, such as predictors of individual service use and domains of need, as well as more nuanced analyses of the differential impact of microsystem, mesosystem, and exosystem factors. The findings of the current study suggest several significant predictors of service and unmet service needs among adults with ASD. However, there are other factors that may explain substantial portions of the remaining variance. For instance, individual, familial and societal health beliefs, symptom perception, and prevention orientation may influence an individual's use of health services (Marcell et al., 2008). Future research is needed to examine how similar psychosocial factors may affect trends of service use in adults with ASD, especially as sex/gender differences have been reported among these variables in the typically developing population (Marcell et al., 2008).

In order to reach as wide a sample as possible, participants were primarily recruited through community services and ASD advocacy agencies and predominantly through online methods. It is possible that the service experiences of adults with ASD who are connected to service providers may differ from those who are not affiliated with community agencies. Further, participants were largely Caucasian and were required to have the capacity to complete the online survey independently. As such, their experiences may not be representative of the wider ASD population. Moreover, relative to current ASD sex/gender prevalence rates (e.g., Loomes et al., 2017), there was an over-representation of female participants in the current study. Similar sex/gender imbalances are often found with online surveys in ASD (Nicolaidis et al., 2013) and non-ASD samples alike (Rhodes, Bowie, & Hergenrather, 2003).

A final caution relates to diagnostic validity. It was not possible to verify participants' ASD, ID, and medical and psychiatric comorbidity diagnostic status, although participants were asked to confirm that they had received formal diagnoses. Future work with objective methods and more detailed analyses of ID, psychiatric, and medical diagnoses would be valuable because service experiences may be more related to ratings of severity and associated functional limitations of these co-occurring conditions.

Conclusion

An important and overarching observation to make from the current study is that women differed from males in reported service experiences in only a minority of instances. This suggests that women with ASD have equally as high service need and utilization patterns as males with ASD. Policies to enhance funding and service availability will be key for all adults with ASD. Taking a broader perspective, however, significant sex/gender differences emerged with respect to both individual and contextual factors. Women live within complex and differing social, economic, and environmental circumstances that influence service patterns (Hankivsky et al., 2010). To ensure appropriate provision of care, it is therefore necessary for future research to continue to identify how the service system interacts with both individual characteristics and the broader sociocultural lives of women with ASD.

Chapter 3: A Qualitative Analysis of the Service Experiences of Women with Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) has historically been diagnosed in a significantly higher proportion of males than females (Baio, 2012; Carter et al., 2007, Fombonne, 2003, 2009). Recent reviews highlight evidence for an altered female ASD phenotype (Kirkovski et al., 2013; Kreiser and White, 2014; Van Wijngaarden-Cremers et al., 2014) and studies have shown that ASD may be harder to detect among female populations (Begeer et al., 2013; Cridland et al., 2014; Giarelli et al., 2010). Autism Spectrum Disorder is considered a lifelong condition and the service needs of adults are often complex and require frequent service use across different service sectors (Barrett et al., 2015). Beyond the limited attention paid to diagnostic concerns, however, the detailed service needs of women with ASD remain relatively unknown. A better understanding of the service experiences of women with ASD is integral to providing quality care to this marginalized population. The current study aimed to qualitatively explore the service experiences of women with ASD in six key service domains: (1) assessment; (2) physical health care; (3) mental health care; (4) social skills development and support; (5) postsecondary educational and vocational services; and (6) residential supports.

Qualitative Research

Diagnostic-related assumptions about symptoms and impairments can lead to research designs that exclude or restrict participation of many individuals with ASD (Harrington, Foster, Rodger, & Ashburner, 2014). Recent research shows an overwhelming preference by stakeholders in the ASD community for more inclusive research methods (Pellicano et al., 2014). While women with ASD may present with a

range of communicative and cognitive abilities, qualitative research methods have been used successfully in past research involving individuals with ASD with diverse abilities and may give voice to participants who have historically gone unheard in the research process (e.g., Bölte, 2014; Ruef & Turnbull, 2002).

Focus groups were used in the current qualitative study to better understand the service experiences of women with ASD. Focus groups are a form of group interview that capitalize on the group communication process to explore and clarify participants' opinions and experiences (Kitzinger, 1995). The goal of the group format is to elicit a discussion that allows the researcher to see the world from the participants' perspectives. Focus groups have been used extensively in health service research to examine individuals' service experiences and may be of particular use with individuals with disabilities because they do not require reading or writing (Kitzinger, 1995). In a recent study looking at factors influencing the research participation of adults with ASD, most participants highly valued their participation in focus groups and the opportunities that the groups availed for interactions with others in a structured format (Haas et al., 2016).

Research Questions

Using focus groups, the current exploratory qualitative study aimed to address the following research questions:

- 1) How do women with ASD perceive their past and current service experiences in the areas of diagnostic assessment, physical and mental health care, social skill development and social supports, postsecondary educational and vocational services, and residential supports?
- 2) What, if any, are the unmet service needs of women with ASD?

3) What, if any, barriers to care do women with ASD identify?

Methods

Participants

A total of 20 women with ASD participated in five focus groups. Participants ranged in age from 19 to 69 years ($M = 35.45$; $SD = 12.26$). The age at which participants were diagnosed with ASD ranged from 2 to 65 years ($M = 26.25$; $SD = 17.24$). No participant had been diagnosed with an intellectual disability (ID). The majority of participants identified as white (90%). Approximately 60% of participants were single, while 40% were married or in relationships. More than half of participants (55%) lived independently/with their spouses or partners (i.e., in own house or apartment), while 45% lived with their family of origin (i.e., with parents). Participants reported their highest education levels achieved as follows: 15% obtained a post graduate degree, 25% graduated university, 40% graduated college or a diploma program, and 20% graduated high school. More than half of participants (55%) were employed or attending school full time, with the remainder unemployed and/or not attending school (30%), employed or attending school part time (10%) or retired (5%).

Procedure

Ethics approval was obtained from York University. Convenience and snowball sampling methods were used to recruit participants from across the greater Toronto area. Participants were recruited from postings on ASD support organizations' websites (e.g., Autism Ontario, Kerry's Place Autism Services) and through email lists associated with these organizations, in addition to a pre-existing database of participants through the Chair of Autism Spectrum Disorders Treatment and Care Research. Participants were

invited to partake in the focus groups if they had been diagnosed with ASD by a qualified healthcare professional and were 18 years of age or older. With an exploratory focus on obtaining varied perspectives, no exclusion criteria were set with regard to cognitive ability and/or comorbid diagnoses. Interested participants were asked to contact the researcher via telephone or email. Once contacted, the researcher discussed the purpose of the study, provided a brief orientation to focus group methodology (Malik, Ashton-Shaeffer, & Kleiber, 1991) and verbally confirmed that the individual had received a diagnosis of ASD by a qualified healthcare professional and would be able to participate in the focus group independent of a caregiver.

All focus groups were held at York University. After informed consent was obtained, participants were asked to complete brief demographic questionnaires (see Appendix A) for descriptive purposes. According to suggested focus group procedure (e.g., Krueger, 1994), a topic guide was created in advance to ensure all relevant topics were covered (see Appendix B). Accuracy checks were conducted at the conclusion of each focus group by summarizing the key questions and major ideas that emerged from the discussion and by asking participants if the summary was adequate, and/or if any important issues had been missed. Participants were reimbursed for their parking costs and given a \$50 honorarium. Funding was provided by the Chair in Autism Spectrum Disorders Treatment and Care Research (#RN284208; *Canadian Institutes of Health Research in partnership with NeuroDevNet, Sinneave Family Foundation, CASDA, Autism Speaks Canada and Health Canada*). The sessions were audio-recorded using a digital voice recorder and transcribed verbatim.

Methodological considerations. Difficulties in social communication and interaction are hallmark features of ASD (American Psychiatric Association, 2013). Many individuals with ASD also experience difficulties with co-occurring sensory, physical and mental health problems (Croen et al., 2015). Accordingly, the following methodological considerations were taken into account to permit the successful participation of all participants: focus group size; provision of sample questions, focus group length and moderation; and environmental accommodations.

Focus group size. The emerging literature on focus groups with participants with intellectual and/or developmental disabilities (IDD) suggest smaller groups may be necessary to allow sufficient time to present questions and for participants to respond (Barrett & Kirk, 2000; Kroll, Barbour, & Harris, 2007). Additionally, past research participants with ASD have expressed concerns about interacting with others in large groups and a preference for smaller groups (Haas et al., 2016). As such, focus groups in the current study were smaller than conventional focus groups (i.e., six to 12 individuals; Krueger, 1994), ranging from two to five participants.

Provision of sample questions, focus group length, and moderation. Individuals with ASD often experience impairments in executive functioning (e.g., cognitive flexibility; fluency; planning; Van Eylen, Boets, Steyaert, Wagemans, & Noens, 2015). Accordingly, participants with ASD may need additional time to clarify the meaning of questions or to provide explanations to researchers about their responses (Haas et al., 2016). In the current study, participants were provided sample questions from the topic guide in advance of the focus group. Additionally, focus groups averaged an approximate

length of 115 minutes, which is slightly longer than the recommended length for a larger focus group (e.g., 60-90 minutes for a group with six to 12 participants; Krueger, 1994).

As the “hallmark” of focus groups is the “explicit use of group interaction to produce data and insights that would be less accessible without the interaction found in a group” (Morgan, 1997, p. 2), care was taken to not ask leading questions and to let discussions develop freely with as little interference from the facilitator as possible, beyond ensuring that all topic areas are covered. However, the discussion was modified as needed to accommodate the needs and abilities of participants (Biklen & Mosely, 1988; Finlay & Lyons, 2002; Malik et al., 1991; Ruef & Turnbull, 2002). For instance, individuals with ASD may have difficulties with directing their attention to the current topic of conversation, and some may perseverate on issues and/or appear unable to move on to follow the flow of the group discussion (Kroll et al., 2007). In the current study, these difficulties were addressed by allowing participants time to talk briefly about their own interests, without asking any follow up questions, and then redirecting their attention back to the next topic guide question or the current topic of conversation (Harrington et al., 2014; Owen, Hayett, & Roulstone, 2004).

Environmental accommodations. Researchers’ inattentiveness to participants’ sensory needs has been highlighted as a potential barrier to research participation among adults with ASD (Haas et al., 2016). In the current study, participants were asked in advance of their sensory needs and suggestions for feasible accommodations. Examples of accommodations included asking other participants to refrain from wearing scented products and the use of dimmed overhead lights. Participants were also encouraged to

inform the facilitator when they required a break, as some individuals stated that they fatigue easily while engaging in group activities in a multisensory environment.

Data Analysis

The software package NVivo 11 was used to allow systematic coding and data retrieval. An inductive, semantic-level analysis of the focus group data was conducted as per the analytic phases outlined by Braun & Clarke (2006, 2013). Semantic-level analyses focus on what participants actually say, rather than on possible underlying conceptualizations to provide a descriptive outline of commonalities of experiences (Braun & Clarke, 2006; 2013). First, transcripts were read for initial impressions. Next, a set of initial codes was generated based on additional close readings of the transcripts. Inclusivity of initial coding was used to ensure both the patterning and diversity within the data was captured (Braun & Clarke, 2013). Codes were then collated into preliminary candidate themes. The integrity of the preliminary themes was checked in relation to their coded extracts and the data set as a whole. Patton's (1990) criteria for establishing themes by assessing internal homogeneity (i.e., collated data within each theme adheres together in a meaningful way) and external heterogeneity (i.e., clear and identifiable differences are evident across individual themes) were used. Conceptualizations of each final theme were refined as needed and exemplary extracts were selected.

Reflexivity. Reflexivity refers to the researcher's identification of pre-existing biases, theoretical assumptions and an awareness of how they may impact data analyses (Glaser, 1978). Memoing is a way of recording a researcher's understanding of the data in addition to identifying and bracketing (i.e., setting aside) pre-existing assumptions about the study. Through memoing, I reflected on the stated assumptions of ecological

and postcolonial feminist frameworks, in addition to my own personal history with individuals with IDD, and the multiple perspectives that I have assumed as a family member, friend, camp counsellor, job coach, therapist and researcher. I acknowledged that the driving force behind the project was a social justice perspective by its very focus on an assumed marginalized group and its explicit goal of informing change in policy and clinical practice. Systematic memoing is thought to enhance the credibility of the data analysis and research findings (Glaser, 1978; Primeau, 2003; Rennie, 1998).

Results

A total of 45 initial codes were collated into candidate themes (see Table 3.1). As shown in Figure 3.1, two overarching themes were identified: “Feeling like the Odd Woman Out” and “Services and Supports: One Size Does Not Fit All”. The four primary themes supporting these two main themes are outlined below: (1) ‘you don’t look like you have autism’; (2) masking service needs; (3) (mis)communication with service providers; and (4) accessing appropriate services: ‘a constant struggle’. Organization of the overarching themes, primary themes and subthemes is represented in Figure 3.1. Within the results below, overarching and primary themes are identified as subheadings and subthemes are identified in italics. Data extracts have been edited minimally to aid readability and comprehension; an ellipsis indicates text not relevant to the analysis has been removed. All data have been anonymized so that identifying information was changed or removed. Participant ID numbers are used to identify quotations.

Feeling like the Odd Woman Out

The overarching theme “Feeling like the Odd Woman Out” captures participants’ nonconforming experiences as female service users with ASD: Odd denotes a marginal

and atypical position and presentation; odd woman highlights normative sex and gender assumptions; and feeling like the odd woman out places participants' service experiences within a discourse of difference. Within this overarching theme, experiences related to belonging and identification were prevalent. Participants frequently acknowledged the tensions they experienced feeling like the odd woman out in varying diagnostic categories, social roles and service systems, as well as their enduring efforts to meet self-imposed and societal expectations.

Most participants were diagnosed with ASD as adults; however, many described lifelong difficulties connecting with others, starting in childhood:

Nobody wanted to play with me and they teased me and I took it so badly. I felt like I really wanted to belong in a group, you know, but I'd end up just standing there and everybody was just so social and open, and I was just so quiet and said nothing. (P19)

These sentiments of feeling out of place extended to present day service experiences for the majority of women. For some, these difficulties related to their experiences as service users with ASD within a mainstream service system. For instance, one participant described her difficulties of attending a Lesbian, Gay, Bisexual, Transsexual, Two Spirited and Queer or Questioning (LGBTQ) support group with typically developing individuals:

If I go to a LGBTQ group and my other friends don't come, if I go by myself, my autism sticks out like a sore thumb. I'm not making eye contact...or I'm talking too much or out of turn. And then I feel like such a failure and miserable and depressed about that...I don't fit in. (P2)

Still, others felt equally out of place in ASD specific services, often due to the male majority: “Now even that I have the label and I could go to that group for Aspies ... but I’m the only girl. So, still, I don’t really belong.” (P19) ASD specific services were also often described to cater to those with more pronounced impairments, which further isolated some participants.

‘You don’t look like you have autism’. A common thread across participants’ experiences related to others dismissing their service needs. Many indicated that this was largely because they were seen as *not looking the part* due to their atypical presentation of ASD. Many participants identified distinct and subtler behavioral manifestations of ASD as compared to the typically overt social challenges and/or disruptive behaviors that many males with ASD exhibit. One participant highlighted the disconnect between her own presentation and the preconceptions of ASD that many hold:

...Me and my parents got doubts from other people with the diagnosis because, you know, you sometimes just don’t fit the cookie cutter definition exactly. I was the quiet and kind girl in school – not the six-year-old boy rocking in the corner or whatever the picture of what people have in their minds of severe autism. (P1)

Such an atypical presentation led to numerous *diagnostic roadblocks* for many participants. Several women indicated that their quiet and subdued presentations in childhood conformed to societal expectations of femininity or being the ‘good girl’, which often meant that participants’ ASD related social difficulties went unnoticed. Participants’ ASD related social difficulties were also often overshadowed by comorbid mental health concerns. The following discussion between three focus group participants highlights these shared experiences:

P19: There was definitely something wrong when I was a child... but I was just the child that was really, really shy- intensely shy- and didn't have friends. But I think because I'm a girl that people sort of think that's in the normal range of girls. They think that-

P16: She's just a sweet kid.

P17: She's just shy!

P16: Sweet, lady-like, right?

P19: Yeah, and a little quirky but very quiet...but when I went to high school it got a lot worse and I ended up sort of falling into some really intense depression that I still have to deal with now.... So, when I was 15, I ended up having to sort of urgently go into more intense psychological intervention with a psychiatrist and they still didn't quite know what the reasons were other than we need to deal with your depression and anxiety.

P16: And then you're just another girl with depression and anxiety.

A large proportion of women recalled numerous encounters with the mental health system and several psychiatric misdiagnoses before being assessed for ASD in adulthood.

Perhaps related to their "sweet, lady-like" presentations and/or the general unfamiliarity and unawareness of the possibility of a female phenotype of ASD, many participants explained their need to initiate their own ASD assessment process. Several women detailed the months, and, in some cases, years, they spent reading ASD literature and researching appropriate ASD assessment service providers. Participants' self-initiative and efforts to seek out a diagnosis were often met with opposition from

informal and formal supports alike; many stated the idea of an *ASD diagnosis does not sit right with others*:

I had lots of family and friends who I sort of mentioned the possibility of ASD to and they'd say to me, 'Oh, no, no, no, no, that's not you.' I think they wanted to reassure me. I think, you know, they wanted to tell me, 'Oh no, you're not defective.' It comes from a place of love but also comes from a place of ignorance of what this thing actually is...and what it means to get a diagnosis. (P15)

Similarly, several participants described their experiences with service providers' misunderstanding of ASD symptomology. Many participants who were diagnosed as adults acknowledged feeling as though "there was sort of a reluctance to give [them] the diagnosis" (P4) because ASD is generally regarded as a childhood disorder. Others felt that many health care professionals demonstrated an overall lack of awareness of the heterogeneous presentations and needs of individuals with ASD. For instance, one participant described the disbelief her psychiatrist expressed when she told him she had been diagnosed with ASD: "He would point out things like, 'Well, you're making eye contact with me, so you can't have autism' and 'You've been married three times so you can't have autism'." (P9)

Despite the general skepticism they encountered, most participants also acknowledged their *ASD diagnosis as an eye opener*. Practically speaking, the diagnosis allowed access to services and directed them towards appropriate resources. On a more emotional level, the diagnosis allowed some participants to make sense of their life-long social and emotional difficulties. One participant explained the validation and self-understanding that she experienced after being diagnosed with ASD at age 40:

So when I did finally get it...she told me at the end of the day, 'Yes, you definitely are Asperger's.' I lost it, just bawling...I was feeling relief, profound relief. It took me several days to process because all of a sudden it had flipped every experience of my life upside down and sideways. When I was young, I used to tell myself in my head, '...You aren't doing anything on purpose. You're trying to act just like everybody else, you're trying with every fibre of your being and people can't see it. Something has to be wrong.' ... That was the little quiet voice that stopped me from killing myself any number of times when I hit rock bottom as a teenager because there was something inside me that said, 'No, there's something wrong.' And then I found out that voice was right all along. (P16)

Many other women, in contrast, identified feeling disappointed after their assessments because their late diagnosis was viewed as contributing to missed opportunities for services and supports.

Masking service needs. Most participants described their ability to “mask” their ASD symptoms (i.e., conceal or compensate for their social communication difficulties) to varying extents and explained a wide range of implications of these masking abilities. For some participants, the ability to *'turn on my normal'* was viewed as a positive coping mechanism they developed as youth, which has extended to adulthood. In some cases, participants were able to articulate explicit strategies that they developed to assist in social interactions, such as waiting “five to 10 seconds after somebody finishes talking... to see if they are going to continue”(P18) as a way of mimicking/approximating appropriate turn taking sequences in conversations. Many also acknowledged more

implicit facets of masking such as a keen social awareness and ability to adapt to their surroundings:

P16: Everybody here has a high level of awareness of themselves and of-

P17: Yes!

P16: We can talk about ourselves and we're aware of how we present and –

P17: Yea, we have that ability to be empathic even though we're socially awkward. We're still tuned in to everything, we just don't know what to do.

P16: And we understand when we do things, like-

P17: Yeah, I'm totally aware when someone sees me as weird.

P16: Exactly! It's like your spidey sense is tingling. It's like, uh-oh, that person has received weirdness now I have to amend my presentation so that I can pass better.

In particular, masking was commonly acknowledged to assist participants in their interactions with peers, particularly at school and in the workplace.

At times, participants' masking skills were also described to negatively impact their interactions with service providers. Many participants described providers' tendency to minimize their service needs due to their masking abilities; service providers insisted on a *seeing is believing* mentality, which conflicted with participants' often incongruent presentation: "I can turn on my normal long enough to sit through a half hour appointment. So, I'm articulating to my doctor that I'm having these issues but to them it doesn't look like it, so there is that disconnect". (P11) Many participants also described fluctuating service needs. That is, they described days when they are able to mask their difficulties and "turn on normal" to perform their day-to-day responsibilities without

issue, as compared to other days when they require more support, mostly due to anxiety and other mental health concerns. Participants spoke of service providers' inability to fully comprehend these varying needs and their tendency to perceive them as malingering or exaggerating their service needs.

Numerous participants described a sense of *hidden hurt of maintaining the front* due to the strong emotional and physical consequences of the energy expended while masking. The effort required to mask their ASD symptoms while interacting with others was described as "exhausting" by several women. Still, many participants described their ability to "pass" on the outside while simultaneously experiencing this internal sense of exhaustion:

I'm not one to make a scene. I don't even want to be in a scene! I try to always be behind the scene! So to the outside observer I'm sure I look passable - no one is going to expect that inside I'm driving myself crazy. (P15)

Some participants also described reaching a point of exhaustion when they "break down" (e.g., fits of yelling and crying) and are unable to mask their difficulties any longer. The ostensibly unobservable precursors to these "breakdowns" were perceived to further perplex service providers.

Compounding their service experiences of masking service needs, many participants also expressed concerns around the *high costs of feeling too 'high functioning'*, and identified their own reluctance to seek help in addition to feeling stigmatized while accessing services. Many described feeling belied by their seemingly unaffected physical presentation and recalled associated feelings of shame for seeking

help. For example, one woman described feeling unworthy of accommodations in university for her sensory sensitivities:

When I was studying, I didn't think I was deserving of special treatment. I thought I should be able to handle it like everyone else. So what did I do? When I wrote my exams, I filed myself in with the rest of everybody else who has to sit in a giant skating rink with 400 other people under blinking and blonking florescent lights. (P4)

Some participants likened their hesitancy to seek help to a trait commonly demonstrated by many women, "We'll handle our problems ourselves." (P19) Others attributed their overall reluctance to access services to past negative experiences. Some also described a perceived double standard attached specifically to women with ASD:

I've noticed regarding the guys with Asperger's that I know... people just dismiss them as, 'Oh, he's being his usual quirky self.' But if I impose the same request and accommodations and whatnot, because I look too high functioning or whatever, I'm too high maintenance or hysterical even. (P12)

Services and Supports: One Size Does Not Fit All

Despite the diversity of services experiences, a prominent theme across the data was the perceived inability of the current service system to meet participants' individualized service needs. The second overarching theme, "Services and Supports: One Size Does Not Fit All", denotes the general sense of inadequacy participants described with respect to their service experiences. The essence of this theme is captured below as one participant described her inability to receive help for "pebbles" (e.g., seemingly minor difficulties, such as anxiety symptoms, career support needs) in a

service system that only has the capacity to assist with “boulders” (e.g., social communication impairments commonly associated with severe ASD):

I'd just be walking fine along the road and then there'd be this little tiny pebble ...I really struggle with going out and asking for help because they're like, 'If you're struggling, clearly this pebble can't be the problem, so we have to deal with this boulder'. The thing is, I have no... problem with the boulder, I've already been dealing with that ...and they're just kind of like, 'We're just going to keep helping you with this boulder' ...Well, I've been waiting for a year for you to help deal with the pebble. I've actually already been dealing with the boulder. The process of trying to get to the point where I could come talk to you today meant I already had to be dealing with the boulder, I'm stuck on the pebble. (P19)

Within this overarching theme, there are expressions of frustration, criticisms and albeit less frequent, positive impressions of services and service providers.

(Mis)Communication with service providers. Participants reported several instances of *not speaking the same service need language* and diverse challenges associated with communicating with service providers. For instance, several women acknowledged communication difficulties related to verbal fluency limitations (i.e., lexical knowledge and retrieval ability), and the problems inherent in having processing speed limitations amidst service providers' time restraints, particularly with medical professionals. A participant described these difficulties with respect to communicating with her family doctor:

She goes really quickly. She'll ask a question and by the time I finish processing it, I'll usually just give a short answer because I feel like that's what I'm supposed

to do. She's always rushing me. After I'm like, 'Oh wait, actually I should have said this, which is relevant' so I don't get to articulate what I actually need to.

Sometimes I also don't understand the way she phrases things but by the time I figure out enough to ask her to clarify, she has already moved on. (P3)

Other identified challenges related to the social nuances of communicating with service providers, including participants' literal and concrete use of language. For instance, one participant described difficulties discerning between appropriate times to explain her physical ailments and time spent engaging in social pleasantries when speaking with her doctor: "I would always be underreporting but I also don't know sometimes when I'm supposed to report those things". (P4)

Miscommunications with service providers regarding sensory sensitivities and pain perception were prominent. Participants' sensory sensitivities and overstimulation while seeking services often related to the lights, sounds, smells and overcrowding of many providers' places of business. Many women described their difficulty communicating these sensory issues to service providers:

...About dentists, I cannot take the feeling of that bib across me... I can't seem to explain properly to them, in the moment, that I would rather have a cavity drilled than have this thing up against my neck the whole time. They say, 'Oh, it will dribble on your clothes' but I don't care and they just don't get it! (P6)

Several participants also identified having a high pain tolerance, while others described challenges in communicating their experience of physical pain to medical professionals due to a seemingly blunted physical presentation. One participant, for example, presented to the emergency department with kidney stones. Despite the pain being so

unbearable she thought she “was going to die”, staff were viewed as less responsive to her because she “was not crying or screaming.” (P10) Some participants also attributed their high pain tolerance and associated difficulties communicating their pain experiences with their ongoing sensory issues. That is, some participants identified a “neurotypical obsession with pain” (P18) on the part of service providers that seemed to dominate the focus of the assessment and treatment provision. This emphasis on pain was viewed as overshadowing participants’ constant sense of sensory overstimulation, which was more problematic than pain per se for many.

Participants often attributed their communication difficulties to their interactions with *(in)experienced experts*. Many women identified service providers’ lack of experience working with individuals with ASD and, in turn, their lack of awareness of the global impact of ASD to be problematic: “My doctor doesn’t understand why I mention that I have Asperger’s... He just probably thinks that it means I’m socially awkward but doesn’t get that it impacts other things”. (P1) A handful of participants, however, described service providers’ positive communication styles, usually those with prior experience working with individuals with ASD:

I just had a really good experience yesterday with my dentist! I was talking to him and he said, ‘What’s been happening with you?’ And I told him about this diagnosis of autism and he said that he had worked for years at a hospital working with kids with autism. As soon as I said that, I felt like he reached into his communication toolbox or something that he’s learned and all of a sudden he was talking to me differently. All of a sudden he was talking a bit slower and leading up to what he was going to do - he gave me fair warning. I always felt very

comfortable with him...but then he became extra good and I never felt so relaxed at the dentist before! (P4)

Relatedly, participants also described the value that they placed on service providers' willingness to listen to their individualized needs and the appreciation they felt when they *felt heard*: "For my daughter's birth I worked with a midwife, which was a really positive experience because they took a lot more time with me and they were a lot more open to discussing Asperger's in relation to my pregnancy." (P8)

Accessing appropriate services is 'a constant struggle'. The large majority of participants identified significant challenges in accessing the services they need. A number of participants identified *not fitting the bill* as they were often deemed ineligible for many supports and services. Many services were noted to be unavailable as participants aged out of the child service system; age was a particularly significant barrier for those participants who received their ASD diagnosis as adults: "I got diagnosed when I was 31 so that meant that I was cut off from most of the funding sources that I could apply to before I even knew I needed them" (P11). Many participants also found themselves to be ineligible to receive supports based on diagnostic exclusionary criteria, which was especially pronounced with respect to the absence of residential supports. Many women who lived with their families expressed a desire to live independently but were unable to, mainly due to financial concerns. These women were unable to access residential support services as they were considered "too high functioning" and did not have a co-occurring ID.

Many women acknowledged '*a broken system*' in describing their difficulties accessing services due to the reactive, as compared to preventative, nature of many

services, particularly with respect to service availability and cost. For instance, some women turned to other service sectors for assistance when they were unable to access residential supports through the developmental service sector; however, they often encountered long waiting lists, a frequently identified barrier across service sectors.

There is no housing available that I know of for people specifically with Asperger's so that's why I went the mental health supportive housing direction.... A couple of years ago, I was in a housing crisis and a mental health crisis, I was homeless at the time, and I was told I would have to wait three years for supportive housing. I recently contacted them again....and I found out because I'm no longer homeless, my wait is now seven years. (P7)

Similarly reflective of 'a broken system', many participants experienced co-occurring mental health concerns (e.g., anxiety, depression) and described their inability to access affordable mental health supports due to their limited financial means and decried the crisis-driven nature of mental health services:

I did DBT [dialectical behavior therapy] for years and bunch of other things as well, I found it incredibly helpful but I had to stop because of the cost. I think there's a real issue there when...all these different medical services are covered but when it comes to these sorts of things, psychological things, you're on your own financially. It's not going to be covered for you unless you show up in crisis. It's like a thrill, it's treated as a thrill rather than a necessity, but it helps me to survive. (P14)

Notwithstanding eligibility exclusionary criteria, lengthy waitlists and prohibitively priced services, many women identified further accessibility challenges

related to finding their way to appropriate services, that is *getting there is half the battle*. For instance, participants frequently commented on a lack of transportation as a barrier to service use. Many explained that they were unable to use public transportation independently for fear of getting lost. Others described sensory sensitivities, which made public transportation a highly inaccessible mode of transportation. One participant commented that she could only travel during hours when there were “no huge crowds bumping and all that.” (P10) While speaking about her desire to attend social functions held by a provincial ASD advocacy and support organization, one woman identified another common barrier, social anxiety, which often compounded her need for transportation to services. She described her sense of social isolation, her desire to attend social programs, and her often-debilitating fear of entering a crowded subway or a room full of people.

Several women spoke about their difficulties locating appropriate services and ongoing concerns regarding service applications and the associated paperwork within differing service systems. These difficulties were often exacerbated by siloed service systems and a lack of integrated care:

It’s hugely challenging for me to face the paperwork and just trying to keep track of the bazillion different people who aren’t talking to each other...I have given up at times just because I’ve had to conserve energy for life. I tell myself that when I’m feeling better in a month, a year, whenever, I’ll get to it because it’s just too much without having...a case manager or something to help you with all that stuff. (P20)

Some participants also acknowledged specific features of ASD, such as individuals' tendency to perseverate on details, as contributing to their service application and navigation issues.

Even when able to successfully access services, participants often faced a host of other challenges. Many participants described feelings of *a square peg in a round hole* as they highlighted a need for individually tailored services. For instance, several participants described experiences with unaccommodating mental health professionals who appeared unable or unwilling to shift their intervention approaches to meet the complex needs of women with ASD. In individual therapy, participants often described difficulties with emotion identification and their therapists' insensitivity or unawareness of these difficulties. Other participants described similarly unsatisfactory experiences of attending group therapy programs:

They hand over that green book 'Mind Over Mood' and just sort of insist that we go through the motions that every Tom, Dick and Harry go through. I kept insisting... I'm different and I don't really need these exercises, but it was always, 'Just do this exercise'. (P14)

Accessing appropriately tailored postsecondary educational and vocational supports was equally as challenging for many participants. While some were able to access effective academic accommodations (e.g., alternative scheduling of examinations, permission for audio-recording of lectures) at the undergraduate university or college level, most women who attended postgraduate programs identified a lack of appropriate services and supports. By the same token, many women identified being "overqualified" for many vocational and employment supports:

I had a really hard time starting into my career so I applied to the employment support program that has an autism program. But because my level of education was so high and I was in such a special field, they didn't think they could help me so I didn't really participate... (P7)

Several participants also discussed how many vocational and employment programs were not well suited for individuals' specific needs nor did they highlight their individual strengths and abilities:

They would try to get me to sign up for Tim Hortons or McDonalds. I'm like, 'I cannot work in this environment'. I had a college certificate, I'm on my way to a degree obviously, and I've had to explain myself so many times. I have nothing against minimum wage work, but it doesn't reflect my own strengths. (P10)

Many women highlighted how employment support services were usually tailored to assist individuals with resume and interview supports and identified an unmet need with respect to on-site employment or vocational maintenance supports. Specifically, many women described the difficulties they encountered maintaining steady employment due to their unpredictable mental health needs.

In the absence of effective formal services, many women highlighted *looking outside the box for support*, and described positive experiences with in-person and online self-advocacy and support groups. Several women described the support they received through social media (e.g., Twitter, Facebook), which often acted as their only source of interaction with other women with ASD. Identified benefits of online supports included convenience and accessibility: "The nice thing about being online is the fact that it's international. If I'm having a crisis at 2 a.m., there's somebody online I can talk to who

gets it.” (P19) A few women also participated in a local in-person support group specifically for women with ASD and acknowledged the support they drew from the shared experiences of other women in the group.

Discussion

This qualitative study is one of the first to provide insight into the service experiences of women with ASD without ID. Overall, the results are consistent with past IDD research in describing a profile of high unmet support needs within mainstream and specialized service systems alike (e.g., Barnhill, 2007; Weiss & Lunsky, 2010).

Participants in the current study described exceptional assessment and diagnostic-related concerns in addition to highlighting nuanced, subjective and gendered barriers to care. A shared perception among participants emphasized that the service needs of women with ASD tend to be disregarded or misunderstood largely because they adhere to a nonconforming image of disability.

Assessment and Diagnostic Service Concerns

Most participants were diagnosed with ASD as adults despite acknowledgement of self and caregiver-identified concerns in childhood. Many women also described a perceived sense of reluctance and opposition from formal and informal supports over obtaining the diagnosis in adulthood. Diagnosis of ASD in adulthood is increasingly recognised as an important clinical issue due to the growing general awareness of the disorder and broadening of diagnostic criteria; the idea of a “lost generation” of male and female adults who were previously excluded from the diagnosis has been noted (Lai & Baron-Cohen, 2015). Recent attention to the issue has highlighted the need for clinicians trained in comprehensive ASD diagnostic assessments across the lifespan, including valid

screening instruments, gold-standard assessment measures, and careful consideration of psychiatric co-morbidity (Russell et al., 2016).

Several findings from this study replicate what others have reported regarding the increased risk of non-recognition and misdiagnosis of girls and women with ASD without ID (e.g., Begeer et al., 2013; Dworzynski et al., 2012). It has been suggested that these sex/gender discrepancies may be due to a socialized view of ASD as particular to boys, leading some professionals to be desensitized to the assessment needs of girls (Giarelli et al., 2010). Another reason that girls with ASD may encounter difficulties during the diagnostic process may be related to their abilities to better conceal or compensate for their ASD symptomatology than are boys (Gould & Ashton-Smith, 2011). This study provides tentative support for a “masking” or “camouflaging” hypothesis among women with ASD. Specifically, most participants described effortful and conscious measures taken to mask underlying ASD-related difficulties in social situations, which may have further complicated their diagnostic assessments. As suggested by Lai and Baron-Cohen (2015), further exploration of female ASD masking processes and the required corollary revisions to diagnostic procedures may increase diagnostic equity between the sexes.

Several women in the current study reported receiving psychiatric misdiagnoses prior to receiving their ASD diagnosis. Many also reported co-occurring symptoms of internalizing problems (e.g., anxiety disorders, depression). Past research has shown misinterpretations of symptoms among females with ASD can lead to psychiatric misdiagnoses (Holtman et al., 2007). In contrast to diagnostic overshadowing among individuals with IDD, where symptoms of a mental health issue are attributed to the IDD rather than evaluated separately as a potentially different underlying disorder (Reiss &

Szyszko, 1983), mental health symptoms may conversely overshadow ASD-related concerns for some women (Kirkovski et al., 2013; Mandy & Tchanturia, 2015).

The wide range of benefits of early ASD identification and intervention are well documented (Zwaigenbaum et al., 2015). Participants in the current study perceived that they would have benefitted from services and supports at a younger age had they received their ASD diagnosis as children. Of particular note, feelings of alienation from others and a sense of *difference* were prevalent among the majority of participants. In describing the experiences of LGBTQ youth self-identifying or “coming out”, Davies (1996) suggests that acquiring a label, and acknowledging shared experience with others, can promote a sense of belonging and acceptance. Indeed, participants in the current study, similar to past research ASD research with predominantly male samples (Powell & Acker, 2016; Punshon, Skirrow, & Murphy, 2009), identified an increased sense of self-understanding following their ASD diagnosis. Similar to a recent qualitative study (Bargiela et al., 2016), several participants also highlighted the value of connecting with others with shared experiences through online and in-person social groups; these connections were made after participants’ were able to identify as women with ASD. The impact of receiving an ASD diagnosis can be profound and multifaceted; further efforts are clearly needed to improve the accuracy of early diagnoses for girls with ASD.

Unmet Service Needs

Participants in the current study described an overall decrease in service availability in the adult service sector; a phenomenon referred to as a “service cliff” in past ASD research (Shattuck et al., 2011; Turcotte et al., 2016). Similar to the current study, past research has also highlighted the challenges many individuals with ASD

experience finding and accessing the few available services in the adult service sector (Shattuck et al., 2011). These difficulties were especially pronounced for the majority of participants who received their diagnoses in adulthood. Post diagnostic support in accessing appropriate services has previously been recognized as an unmet service need among individuals with ASD who receive their diagnoses in adulthood (Punshon et al., 2009). Additionally, many participants in the current study described complex needs necessitating a range of services across sectors; however, case management services were identified as a particularly salient unmet service need. While case management is considered crucial for the optimal utilization of health care services for people who have complex needs requiring multidisciplinary expertise (Walsh, Kastner, & Criscione, 1997), many adults with ASD are ineligible for the service as it is often only available through the developmental service sector for individuals with ID.

This study highlighted concerns with mental health services for women with ASD. Participants' concerns about the availability, affordability and effectiveness of extant mental health supports are echoed in the ASD and broader IDD literature (e.g., Griffith et al., 2011; Weiss & Lunsky, 2010). Many participants described fluctuating anxiety and depression and their inability to access preventative services in a crisis-driven service system; caregivers of individuals with IDD have voiced similar concerns in past research (Black, Malaison, & Smull, 1990; Burton- Smith et al., 2009; Weiss & Lunsky, 2010). Perhaps more specific to women with ASD, participants in the current study also described mental health support needs related to the emotional energy required to camouflage or mask their social communication difficulties and the associated negative repercussions on their psychological wellbeing. Although such camouflaging behavior

may occur across sexes/genders, it appears to be more likely in females (Lai et al., 2016). Overall, few studies to date have comprehensively studied masking strategies of women with ASD (Bargiela et al., 2016; Hull et al., 2017; Lai et al., 2016; Rynkiewicz et al., 2016; Tierney et al., 2016); a greater understanding of these challenges will allow clinicians to better tailor appropriate services and supports.

Past research has found that less than half of adults with ASD live fully independently (Anderson et al., 2014). In the current study, 55% of participants lived independently, possibly speaking to the higher adaptive abilities and lack of ID in the sample. Nonetheless, several participants who lived with family, in addition to those living independently, voiced dissatisfaction with their current living arrangements and their inability to access residential supports through the developmental service sector without an associated ID. Past work has highlighted stark differences in independent living rates between young adults with ASD and young adults with ID with the proportion of young adults with ASD reported to have ever lived independently significantly lower than those with ID (Anderson et al., 2014; Shattuck et al., 2012); these differences may reflect an important service gap.

Consistent with past ASD research (Anderson et al., 2014), availability of financial resources was a primary factor associated with participants' need for residential supports. Numerous studies have found that adults with ASD experience several challenges in securing and sustaining competitive employment (e.g., Barnhill, 2007; Muller et al., 2003). Similar to past research (Hurlbutt & Chalmers, 2004), participants described lengthy histories of unemployment and "mal-employment" (a variant of underemployment in which the quality of employment is inferior relative to the potential

productive abilities of the worker; Feldman, 1996). Relatedly, many participants identified unmet service needs with respect to vocational and employment support services. Specifically, participants described their negative experiences with employment supports that predominantly focused on skill training related to finding and applying for jobs (e.g., resume and interview support) and the relative ineffectiveness of extant supports in assisting them in job maintenance skills (e.g., on-site coaching to cope with the demands of their jobs). Past research on supported employment schemes for adults with ASD has identified key elements associated with success to include careful job placement and prior job training in addition to follow-up monitoring, advocacy skill training, and long-term support to ensure job retention (Mawhood & Howlin, 1999). While the provision of ongoing employment maintenance supports has considerable financial implications, research has shown that the cost-benefit ratio of enhancing employment supports for adults with ASD is beneficial from a long term economic standpoint (Jacob, Scott, Falkmer & Falkmer, 2015; Mavranouzouli et al., 2014).

To summarize, participants in the current study described diverse unmet service needs in the adult service sector. They highlighted areas of particular concern with respect to case management, mental health services, and residential and employment supports, common to the issues felt by a broader range of adults with IDD. More specific to women with ASD though, participants also described difficulties with assessment and diagnostic services, and support needs associated with mental health repercussions of masking or compensating for their social communication difficulties. Broadly, participants spoke about the difficulties of accessing developmental services without an associated ID, in addition to their challenges receiving adequate support within the

mainstream service system. The development of systems for personalizing services and supports to the needs of individual service users with IDD, commonly referred to as person centred services, has become fundamental to current health and social care policies in Canada and elsewhere (e.g., Martin, Ashworth , & Ouellette-Kuntz, 2012; Ministry of Community and Social Services, 2013; Scottish Executive, 2000). Given the individuality of women with ASD and their differing support needs and the context with which they are often identified, future research is needed to determine effective person centered approaches to services tailored to the individual, as opposed to the current model of existing services that women need to “fit into”.

Barriers to Care

Overall, many participants felt their service needs were eclipsed by their cognitive abilities, educational achievements, and masking of social and communication challenges. Baldwin and Costley (2016) proposed that while women with ASD without ID do not demonstrate the same adaptive behavior deficits as those of individuals with mild or borderline ID, there are certain similarities in their expressed barriers to care. Indeed, many participants in the current study described challenges accessing required supports and services due to a perceived “cloak of competence” (Egerton, Bollinger, & Herr, 1984). That is, many women perceived service providers to hold unattainably high expectations given their lack of apparent physical or adaptive behavioral deficits, which often led to the minimization or disregard of their stated service needs. Similar to individuals with mild ID (Snell et al., 2009), participants also described how a failure to meet service providers’ high expectations was frequently met by dissatisfaction from others (e.g., a service provider expressing frustration when a participant had difficulty

completing an application form) and/or the individual blaming herself (e.g., a participant feeling unworthy of testing accommodations for sensory needs in school).

Many participants described barriers to care associated with perceived stigma about ASD, and more broadly, women and disability. Werner and Malterud (2003) documented accounts of women with chronic pain and the effortful work that was needed to make their symptoms socially visible, real, and physical when consulting service providers. The overall minimization of participants' service needs in the current study may be similar to the narrative of many women with chronic illnesses who often find themselves being questioned and judged either to be not ill or given a psychiatric misdiagnosis (Werner & Malterud, 2003). More generally, women have been historically disadvantaged in medical research, treatment and related research, which is known to impact clinical consultation and decision making practices (McMurray et al., 1991).

Service providers' knowledge, skills, and attitudes were frequently cited as barriers to effective care. The general sense that providers lacked knowledge about how ASD may manifest in women and associated care implications is consistent with other studies identifying more general gaps in service providers' knowledge and understanding of ASD (Bruder et al., 2012; Nicolaidis et al., 2015). In particular, several participants described difficulties communicating their pain experiences. While the evidence for atypical pain thresholds of individuals with ASD is mixed (Duerden et al., 2015; Moore, 2015), challenges with body awareness may complicate how some individuals with ASD are able to identify and communicate their pain experiences to healthcare providers (Nicolaidis et al., 2015). Participants also identified feeling "rushed" while interacting with service providers, particularly medical doctors. Warfield et al. (2015) identified

several themes related to the financial disincentives of providing care for adults with ASD for physicians, including the extra time it may take to care for a patient with ASD in office, the frequent need to connect with other care providers, and the lack of reimbursement for that time, which results in lost revenue. Past research has suggested systemic reforms are needed to incentivize providing care for patients with complex needs, including adults with ASD (Campbell, McDonald, & Lester, 2008; Mandell, 2013; Warfield et al., 2015).

Research in the typically developing and IDD literature has documented a relationship between service inequalities and structural social factors, such as socioeconomic status (Denton & Walters, 1999; Stancliffe & Lakin, 2005). In summarizing the research on individuals with IDD, Stancliffe and Lakin (2005) emphasize the all-encompassing effects of poverty and un/under employment on service access and use. In the current study, many participants identified affordability of services as a significant barrier to their service use. Several participants also identified lack of accessible and affordable transportation as impeding their service use; similar issues are known to impact service use patterns of predominantly male sample of adults with ASD (Shattuck et al., 2011).

In sum, several factors aggravated participants' challenges accessing services, including a perceived "cloak of competence", perceived stigma and disability biases and resulting minimization of service needs, service providers' lack of knowledge of ASD, and socioeconomic inequalities. The intersection of sex/gender, disability and structures of socio-economic status is an area of ongoing debate in the general literature (Gerschick,

2000); further research is needed to better understand associated implications for women with ASD.

Limitations

This study is limited in that it is not representative of all women with ASD. Most participants were diagnosed with ASD in adulthood, had some post-secondary training or education and identified as white; no participant reported being diagnosed with an ID. It is difficult to predict how these characteristics shaped the results of the current study. Additionally, participants were recruited through community service and ASD advocacy agencies and largely through online methods. These recruitment methods may have led to sampling bias as the experiences of women who are connected to service providers and/or have access to online information may differ from those who are not connected to agencies and/or do not have Internet access. It is also possible that individuals who self-referred for this study were more dissatisfied than the typical woman with ASD, or are of specific socioeconomic conditions that enable self-advocacy, and thus may not be representative of women who are marginalized or those who are more satisfied with services.

Although group interaction is generally seen as an advantage of focus groups, there is always the possibility that the social demands within the group setting may inhibit interaction for some participants (Lewis, 1992; Kitzinger, 1995). In this study, individual participants may not have felt comfortable responding openly within the group format, possibly resulting in minimized contributions. However, considerable attention was paid to how the focus groups were conducted to best ensure participants' comfort (e.g., measures taken during the interview to give participants time and space to

contribute). Additionally, past research has shown no overall differences in the number or quality of ideas generated when comparing focus group to individual interview methods with typically developing research participants (Fern, 1982). Nonetheless, preliminary research has demonstrated successful results with Internet facilitated interviews with adults with ASD (Barnett & Maticka-Tyndale, 2015); given the relevant logistical (e.g., limited transportation) and clinical (e.g., social anxiety concerns) issues described by many participants in the context of service access barriers, this could be an important area to further explore as a more inclusive and accessible research method for some women with ASD.

Finally, while all women reported they previously received ASD diagnoses by qualified health care professionals, no objective diagnostic confirmation of ASD was used in the current study. Future research would benefit from the inclusion of ASD symptomatology measures.

Conclusions

The current study demonstrated that increased awareness by researchers, service providers and policy makers of the range of subtle and subjective ways that ASD may manifest itself and is experienced by women is clearly needed. Effective individualized supports for women with ASD depend on timely, accurate and ongoing assessment of needs and monitoring of outcomes coordinated across service sectors. Future research is required to identify variables associated with successful pathways to care for this understudied population.

Chapter 4: Mixed Methods Integration

Historically, women with Autism Spectrum Disorder (ASD) have represented a vastly understudied population (Watkins et al., 2014). Recently, an increasing number of studies have attempted to clarify the nature of sex/gender differences in clinical presentations of ASD (e.g., Backer van Ommeren, Koot, Scheeren, & Begeer, 2017; Grove, Hoekstra, Wierda, 2017; Hull et al., 2017). In tandem with this growing knowledge of the unique characteristics of girls and women with ASD, it is important to better understand the associated pragmatic impact on lived experiences. With this aim, the current mixed-methods project provided an exploratory description of the service experiences of women with ASD.

This project followed a concurrent mixed methods design with data collection and semantic analyses taking place in two distinct phases. The quantitative phase consisted of online survey data and provided a descriptive analysis of lifetime service use, unmet service needs, and barriers to care of women and men with ASD from across Canada. Few sex/gender differences emerged, with the exception of mental health and residential services. However, a number of significant associations between service outcome variables and micro, meso, and exo system factors were found. In the qualitative phase, focus groups with women with ASD without intellectual disability (ID) identified key themes related to unmet service needs, particularly with respect to mental health concerns, residential supports, and vocational and employment services. Participants emphasized their perceptions of many service providers disregarding or misunderstanding the female presentation of ASD.

Commonly acknowledged strengths of mixed methods research designs focus on triangulation and complementarity (Creswell, 2003; Creswell et al., 2011; Johnson et al., 2007; Sale, Lohfeld, & Brazil, 2002). Wading into the ontological and epistemological debate of quantitative-qualitative methods, Sale and colleagues (2002) argue that implementing both qualitative and quantitative methods is not to study the same phenomenon, but different ones. Combining the results of the two phenomena enhance the understanding of targeted research questions. To this effect, the current study used quantitative elements to ask ‘how many’ in order to measure, predict and correlate variables related to sex/gender differences in service use, unmet needs, and barriers to care. Qualitative methods asked ‘what’ and ‘how’ in order to explore underlying and unique issues in the service experiences of women with ASD. What follows is an integration of the project’s quantitative and qualitative findings with the goal of further broadening a comprehensive understanding of the service experiences of women with ASD. First, quantitative and qualitative results are discussed with respect to areas of incongruence, corroboration, and elaboration. Next, deductive, latent (re)interpretations of phenomena are detailed within the project’s ecological and post-colonial feminist theoretical frameworks. Finally, limitations of the current project and suggested directions for future research are provided.

Areas of Incongruence, Corroboration, and Elaboration

The overarching qualitative themes of ‘Feeling like the odd woman out’ and ‘Services and supports: One size does not fit all’ focus on a sense of *difference*. Women described their atypical clinical presentations and service needs that were perceived to differ from the convention –those based on men with ASD. However, quantitative results

largely did not support statistically significant sex/gender differences. Overall patterns of service use, unmet service needs, and difficulty in accessing services did not differ by sex/gender. When quantifying with total counts, the service experiences of women and men with ASD appear to share more similarities than differences.

Conceivably, women's qualitative sense of *difference* may relate to the incongruence of a child-oriented service system that is ill equipped to meet adult ASD-specific service needs, regardless of sex/gender. For instance, qualitative results highlighted women's difficulties related to residential and employment supports (e.g., service eligibility requirements). Quantitative results similarly indicated residential services and employment supports among the most frequently reported unmet service needs for both women and men, and likewise have been noted to be significant areas of systemic service gaps in the overall adult ASD literature (Roux et al., 2013; Taylor & Seltzer, 2011). In speaking of their difficulties obtaining a diagnosis of ASD in adulthood, several women in the qualitative study described how professionals, friends, and family members regarded ASD as a childhood disorder. However, individuals with ASD spend the majority of their lives, and use the majority of health services, as adults (Ganz, 2007). Nonetheless, continued thinking of ASD as a phenomenon of childhood may abdicate the service system of responsibility of care across the lifespan; this misinformed zeitgeist may account for many of the difficulties individuals with ASD, women and men alike, encounter in the adult service sector.

Applying a broader lens to service experiences, however, may further clarify incongruent sex/gender-based differences in qualitative and quantitative results. While women's quantitative outcome measures (e.g., total service use count) may approximate

that of men, their overall service experience - from start (e.g., factors associated with service access) to finish (e.g., associated feelings after service interactions) - may qualitatively differ. In support of this interpretation, quantitative results demonstrated women with ASD identified significantly more barriers to care than men (e.g., not enough resources; negative experiences with professionals in the past; lack of trained professionals) and qualitative results provided further nuanced corroborations and elaborations on sex/gender distinct barriers. Specifically, the impact of camouflaging or masking social communication impairments was a prominent tenet underlying women's qualitative descriptions of their service experiences. Masking, or the ability to '*turn on my normal*', was noted to complicate initial ascertainment and diagnosis of ASD, obscure service needs during interactions with service providers, as well as contribute to women's own reluctance or hesitation in seeking services. A range of service access difficulties associated with masking may have contributed to women's increased identification of barriers to care in the quantitative study, as compared to men.

Ecological and Postcolonial Feminist (Re)Interpretations

Service use, service needs, and related concepts associated with service experiences can be conceptualized as the interaction, or 'degree of fit', between the health system and the individual (Thiede et al., 2007). In taking an ecological perspective, an individual exists within different relational systems, including microsystems (e.g., family), mesosystems (e.g., community and peers), and exosystems (e.g., social and governmental institutions; Bronfenbrenner, 1979). Post-colonial feminism is a theoretical lens that draws attention to the forces that sustain and foster uneven relations of power based on historical positioning, class, race and sex/gender (Anderson & Reimer-Kirkham,

1999). Using both ecological and post-colonial feminist frameworks, the current project underscores three intersecting identities women with ASD embody within their service experiences: they are disabled in a largely able-bodied society; they are of female sex/gender, with women commonly acknowledged to face more barriers and subjugation than men; and they are a female minority within the male-centric ASD world.

A medical model of health is aimed toward normalization, symptom reduction, and elimination of conditions based on functional impairment (American Psychiatric Association, 2000; Baker, 2011). Within a medical model, women with ASD demonstrate individual characteristics that hinder their service experiences. In the current project, women described social communication difficulties associated with relaying their service needs to clinicians, as well as executive function deficits, such as challenges facing “the paperwork and just trying to keep track of the bazillion different people” required to coordinate their care. Moreover, women’s masking behaviors and attempts to correct these perceived deficits, appeared to play a substantial role in their challenging service experiences. In the semantic analysis of qualitative results, further research on women’s unique clinical presentations and masking abilities was called for to allow clinicians to appropriately tailor interventions. That is, a better understanding of women’s behavior is purportedly needed to allow clinicians to identify effective mechanisms of altering and/or mitigating the associated disabling outcomes.

Adopting a social model of disability (Shakespeare, 2006), however, emphasizes factors external to the individual that may cause disabling features. A recent study (Cage, Di Monaco, & Newell, 2017) examined the impact of perceptions of autism acceptance on the mental health of adults with ASD. Findings showed that individuals’ depression

was predicted by autism acceptance from external sources (e.g., family and friends). Additionally, those who reported camouflaging or masking their ASD traits reported higher symptoms of depression. These results, along with the current project's quantitative and qualitative findings focused on women's perceived sense of difference and service difficulties associated with attempts to mask these differences, may indicate a need to shift the focus of future research away from interventions focusing on the individual, and toward systemic and macro level understanding and autism acceptance. Perhaps a greater level of acceptance would enable individuals with ASD to forgo masking, and thus lead to fewer negative implications, including associated mental health concerns and dismissed or misunderstood service needs.

This premise is in line with the rise of the neurodiversity movement (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013). Autistic advocates of neurodiversity tend to adopt a form of the social model of disability, distinguishing between an underlying biological disorder and disability rooted in social and political infrastructures (Baker, 2011). While the term 'disorder' implies an individual's underlying cognition or neurobiology is dysfunctional in some manner, there is little evidence of dysfunction in the cognition and neurobiology of autism, but rather that of difference (Baron-Cohen, 2017). In a recent editorial, Baron-Cohen (2017) highlights a quote attributed to Einstein, "A fish will appear as having a disability if required to climb a tree", as well as an expansion attributed to an individual with autism, "We are fresh water fish in salt water. Put us in fresh water and we are fine. Put us in salt water and we struggle to survive" (Baron-Cohen, 2017, p. 746). To this effect, the challenges women with autism encounter

while accessing services may relate less to their own *difference* and more to the current medical model's focus on pathologising and normalization.

In addition to the impact of disability, participants' sex/gender alone likely contributed to differential service experiences and disparities. For example, women with ASD reported significant employment support needs. In past studies, women with ASD have reported incidents of overt mistreatment in the workplace (Baldwin & Costley, 2016) and greater difficulty than men with ASD in maintaining employment (Taylor & Mailick, 2014; Taylor et al., 2015). Researchers have hypothesized that workplace environments may be less accepting of the needs of women with ASD, which may be perceived as more atypical in women than in men, and/or there may be less of an implied societal expectation for women with ASD to work outside of the home (Taylor & Mailick, 2014). Across social contexts, gender nonconforming behavior of women with ASD may be misunderstood in the absence of overt behavioral problems, particularly among those without ID (Baldwin & Costley, 2016). To this point, recent qualitative research highlights the difficulties many women with ASD experience meeting gendered stereotypes and fulfilling traditionally feminine gendered roles, describing a sense of a 'lost identity' (Bargiela et al., 2016). Similarly, in a review of online surveys, blogs and autobiographies, Davidson and Tamas (2016) noted the emotional cost associated with attempts to conform to gender stereotypes for many individuals with ASD, and the tendency for some to consequently reject or neglect a binary gender identity. Indeed women with ASD, as compared to women without ASD, are more likely to report variant gender identities (Dewinter et al., 2016). While not explicitly explored in the current

project, service implications of gender nonconformity among individuals with ASD merits further study.

To fully understand participants' service experiences, it is important to contextualize women's experiences within a life course perspective (e.g., Elder, 1994). Exposure to stressors across the lifespan can be cumulative and is known to affect epigenetic, psychosocial and physiological outcomes (Allen, Balfour, Bell, & Marmot, 2014). Given women's historical subordinate position in society, men typically have more education, higher incomes, greater political influence, and fewer restrictions on behavior. Likewise, feminist authors emphasize the disproportionate burden placed on women with ASD as professional and personal caregivers (Bumiller, 2008; Meredith, 2003). It follows that sex/gender based service disparities among adults with ASD in the current study reflect micro, meso, exo and macro systemic inequities in opportunities, responsibilities, and roles throughout the life course.

Males with ASD have long overshadowed females in autism specific research and clinical practice. Initial case series first describing ASD were comprised of either predominantly male samples (Kanner, 1943) or on boys exclusively (Asperger, 1944). Many subsequent clinical and epidemiological studies have similarly documented a male preponderance in prevalence, with the male-to-female ratio in ASD among clinical samples typically converging at 4-5:1 (Christensen et al., 2016; Raz, Weisskopf, Davidovitch, Pinto, & Levine, 2015). However, a recent meta-analysis showed that when active case ascertainment is applied in large-scale epidemiological studies, the ratio is 3.25:1, whereas when passive case ascertainment is used the ratio is 4.56:1 (Loomes et al., 2017). Differences in population versus clinical estimates highlights the under-

recognition of ASD in females in real-life clinical practices, and is likely indicative of an identification bias towards males. This bias may relate to how the diagnostic concept of ASD has been formulated, as well as the interpretations of referral sources (e.g., parents, teachers) and clinicians alike, resulting in missed identification (Kreiser & White, 2014). Regardless of the source of sex/gender bias, results from the current project demonstrate associated service implications for women with ASD across the lifespan. Women's access barriers and receipt of ineffective services and supports were pervasive across sectors and highlight the current tension between sex/gendered expectations of ASD service provision based on the male majority, and the marginalization of women's unique service needs: "they...just sort of insist that we go through the motions that every Tom, Dick and Harry go through. I kept insisting... I'm different."

Limitations and Future Directions

There are several important limitations that must be considered when interpreting results of the current project. As previously discussed, ethnicity was measured broadly as Caucasian versus non-Caucasian and both samples consisted predominantly of highly educated individuals without ID, which may limit generalizability to more diverse populations. Of note, the lack of diversity in the current studies may be particularly concerning given the recognized service inequities associated with racial minorities (Liptak et al., 2008; Mandell et al., 2009; Rosenberg, Zhang, & Robinson, 2008). Research from the US has shown individuals from low income and minority groups receive ASD diagnoses at a later age and, when they are diagnosed, they are more likely to require greater levels of support and to have ID (Liptak et al., 2006; Mandell et al., 2009). Considering similar diagnostic delays among girls and women (Duvekot, van der

Ende, & Verhulst, 2017; Dworzynski et al., 2012), a better understanding of the intersectional experiences of those with ID, and minority women with ASD remains an important area for future research.

Further related to limitations of sample diversity, and as previously mentioned, individuals with ASD are more likely to report variant gender identities (Dewinter et al., 2017; May, Pang, & Williams, 2017) as compared to those without ASD. The current project included only individuals who identified as cisgender; however, it will be important for future research to include the experiences of gender-variant individuals with ASD. Moreover, to fully understand the intersection of sex/gender and disability, future studies inclusive of both men and women with ASD, typically developing individuals, as well as those with other special health care needs are needed.

An additional limitation relates to ASD diagnostic validity. Participants in the quantitative and qualitative studies alike were required to have received an ASD diagnosis from a qualified health care professional. The issue of ASD diagnostic validity, however, is convoluted as research into ASD sex/gender differences is at an early stage, and there is growing awareness concerning women with the autism phenotype (i.e., difficulties with social reciprocity, social communication, and sensory processing) who do not formally meet current ASD diagnostic criteria (Dworzynski et al., 2012). Given the possibility that these women fail to meet diagnostic criteria due to ascertainment biases and/or limitations of current diagnostic measures, it will be important for future research to understand their experiences in a service system where care provision is often contingent on formal clinical diagnoses.

Lastly, a strength of the current project lies within its first person account of women's service experiences. However, in keeping with an ecological framework, it will be important for future research to cast a wider net to fully understand the phenomena from different micro, meso, and exosystem perspectives. That is, the contributing viewpoints of families of women with ASD, service providers, as well as policy makers are needed to identify appropriate mechanisms of change to improve service access and delivery for women with ASD.

Conclusion

This mixed-methods project provided an exploratory analysis of the service experiences of women with ASD. Ecological and post-colonial feminist theoretical frameworks raised analysis beyond the micro level to provide an enquiry into the multifaceted socioeconomic, historical, and political forces that shape women's service experiences. By viewing this population's situation within a larger social context, potential sources of social inequalities are exposed and emphasize the importance of adopting a sex/gender informed approach to service provision for women with ASD.

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Table 2.1.

Distributions of Categorical Variables by Sex/Gender (n = 141)

Variable	Total Sample ^a n(%)	Women ^b n(%)	Men ^b n(%)	χ^2	Φ
<i>Microsystem</i>					
ID status				0.23	.04
ID	26(18.4)	14(20.0)	12(16.9)		
No ID	115(81.6)	56(80.0)	59(83.1)		
Medical comorbidity				5.06*	.19
No comorbid condition	29(20.6)	9(12.9)	20(28.2)		
At least one comorbid condition	112(79.4)	61(87.1)	51(71.8)		
Psychiatric comorbidity				7.12**	.23
No comorbid condition	29(20.6)	8(11.4)	21(29.6)		
At least one comorbid condition	112(79.4)	62(88.6)	50(70.4)		
Financial status				5.49*	.20
Financial difficulty	51(36.2)	32(45.7)	19(26.8)		
No financial difficulty	90(63.8)	38(54.3)	52(73.2)		
Education				2.57	.14
High school or less	45(31.9)	22(31.9)	23(32.4)		
College diploma	46(32.6)	19(27.5)	27(38.0)		
Undergraduate degree	32(22.7)	19(27.5)	13(18.3)		
Graduate or professional degree	17(12.1)	9(13.0)	8(11.3)		
Missing	1(0.7)	1(1.4)	0(0)		
<i>Mesosystem</i>					
Community size				1.37	.10
Remote/rural	26(18.4)	15(21.4)	11(15.5)		
Suburban	48(34.0)	21(30.0)	27(38.0)		
Urban	67(47.5)	34(48.6)	33(46.5)		

^a n = 141; ^b n = 70; ^c n = 71

* p < .05, ** p < .01

Table 2.2.

Distributions of Continuous Variables by Sex/Gender (n = 141)

Variable	Total Sample ^a	Women ^b	Men ^c	<i>t</i>	<i>d</i>
	<i>M(SD)</i>	<i>M(SD)</i>	<i>M(SD)</i>		
<i>Microsystem</i>					
Age	35.74(10.73)	36.03(11.61)	35.45(9.85)	-0.32	0.05
<i>Exosystem</i>					
Barriers	3.09(2.33)	3.64(2.40)	2.54(2.12)	2.90**	0.49

^a *n* = 141; ^b *n* = 70; ^c *n* = 71

** *p* < .01

Table 2.3.

Correlations Among Microsystem Variables (n = 141)

Variable	1	2	3	4	5
1. Age					
2. Education ^a	.16***				
3. ID status	-.05	.10			
4. Financial status	-.02	.15	.02		
5. Medical comorbidity	.07	.15	.06	.31***	
6. Psychiatric comorbidity	-.04	.14	.15	.24**	.31***

Note: Point biserial correlation coefficients are reported for dichotomous categorical and continuous variables, eta squared is calculated for continuous and categorical variables with more than two levels, and phi coefficients are reported for two categorical variables.

^a $n = 140$

** $p < .001$; *** $p < .001$

Table 2.4.

Lifespan Service Use by Sex/Gender (n = 141)

Service Used	Total Sample <i>n</i> (%)	Women ^a <i>n</i> (%)	Men ^b <i>n</i> (%)	χ^2	Φ
Family physician ^c	106(75.2)	55(78.6)	51(71.8)	0.86	.08
Postsecondary educational	99(70.2)	49(70.0)	50(70.4)	0.003	- .01
Mental health	89(63.1)	53(75.7)	36(50.7)	9.47**	.26
Employment	64(45.4)	27(38.6)	37(52.1)	2.61	- .14
Social skills	47(33.3)	23(32.9)	24(33.8)	0.01	- .01
Residential	11(7.8)	5(7.1)	6(8.5)	0.08	- .02

^a *n* = 70; ^b *n* = 71; ^c Family physician was assessed in relation to service use in past year only

***p* < .01

Table 2.5.

Bivariate Associations of Mental Health Service Use (n = 141)

	Mental Health Service Use ^a n(%) or M(SD)	No Mental Health Service Use ^b n(%) or M(SD)	χ^2 / t	Φ / d
<i>Microsystem</i>				
Age	35.83(10.84)	35.58(10.64)	0.14	0.02
Education			0.52	.06
High school or less	29(33.0)	16(30.8)		
College diploma	27(30.7)	19(36.5)		
Undergraduate degree	21(23.9)	11(21.2)		
Graduate degree	11(12.5)	6(11.5)		
ID (yes)	14(15.7)	12(23.1)	1.18	-.09
Financial difficulty (yes)	36(40.4)	15(28.8)	1.91	.12
Medical comorbidity (yes)	73(82.0)	39(75.0)	0.99	.08
Psychiatric comorbidity (yes)	85(95.5)	27(51.9)	38.16****	.52
<i>Mesosystem</i>				
Community size			6.02	.21
Remote/rural	21(23.6)	5(9.6)		
Suburban	25(28.1)	23(44.2)		
Urban	43(48.3)	24(46.2)		
<i>Exosystem</i>				
Barriers	3.43(2.28)	2.50(2.31)	2.32*	0.41

^a n = 89; ^b n = 52

*p < .05; **** p < .001

Table 2.6.

Unmet Service Needs by Sex/Gender (n = 141)

Unmet Service Need	Total Sample <i>n</i> (%)	Women ^a <i>n</i> (%)	Men ^b <i>n</i> (%)	χ^2	Φ
Residential	58(41.1)	32(45.7)	26(36.6)	1.20	.09
Social skills	57(40.4)	31(44.3)	26(36.6)	0.86	.08
Employment	31(22.0)	19(27.1)	12(16.9)	2.16	.12
Mental health	16(11.3)	7(10.0)	9(12.7)	0.25	-.04
Postsecondary educational	15(10.6)	9(12.9)	6(8.5)	0.72	.07

^a *n* = 70; ^b *n* = 71

Table 2.7.

Difficult to Obtain Services by Sex/Gender (n= 141)

Difficult to Obtain Service	Total Sample <i>n</i> (%)	Women ^a <i>n</i> (%)	Men ^b <i>n</i> (%)	χ^2	Φ
Mental health	53(37.6)	32(45.7)	21(29.6)	3.91*	.17
Residential	51(36.2)	31(44.3)	20(28.2)	4.20*	.17
Employment	49(34.8)	23(32.9)	26(36.6)	0.22	- .04
Social skills	43(30.5)	20(28.6)	23(32.4)	0.24	- .04
Postsecondary education	37(26.2)	21(30.0)	16(22.5)	1.11	.09

^a *n* = 70; ^b *n* = 72

* *p* < .05

Table 2.8.

Bivariate Associations of Difficulty Obtaining Mental Health Services

	Difficulty Obtaining Mental Health Service ^a <i>n</i> (%) or <i>M</i> (<i>SD</i>)	No Difficulty Obtaining Mental Health Service ^b <i>n</i> (%) or <i>M</i> (<i>SD</i>)	χ^2 / t	Φ / d
<i>Microsystem</i>				
Age	38.13(11.02)	34.30(10.35)	2.08*	0.36
Education			2.69	.14
High school or less	21(40.4)	24(27.3)		
College diploma	15(28.8)	31(35.2)		
Undergraduate degree	11(21.2)	21(23.9)		
Graduate degree	5(9.6)	12(13.6)		
ID (yes)	9(17.0)	17(19.3)	0.12	-.03
Financial difficulty (yes)	27(50.9)	24(27.3)	8.03**	.24
Medical comorbidity (yes)	47(88.7)	65(73.9)	4.44*	.18
Psychiatric comorbidity (yes)	49(92.5)	63(71.6)	8.81**	.25
<i>Mesosystem</i>				
Community size			1.68	.11
Remote/rural	12(22.6)	14(15.9)		
Suburban	15(28.3)	33(37.5)		
Urban	26(49.1)	41(46.6)		
<i>Exosystem</i>				
Barriers	4.57(2.03)	2.19(2.02)	6.74***	1.18

^a *n* = 53; ^b *n* = 88

* *p* < .05; ** *p* < .01; *** *p* < .001

Table 2.9.

Bivariate Associations of Difficulty Obtaining Residential Supports

	Difficulty Obtaining Residential Supports ^a <i>n</i> (%) or <i>M</i> (<i>SD</i>)	No Difficulty Obtaining Residential Supports ^b <i>n</i> (%) or <i>M</i> (<i>SD</i>)	χ^2 / t	Φ / d
<i>Microsystem</i>				
Age	36.94(10.60)	35.06(10.80)	1.00	0.18
Education			1.94	.12
High school or less	19(37.3)	26(29.2)		
College diploma	16(31.4)	30(33.7)		
Undergraduate degree	12(23.5)	20(22.5)		
Graduate degree	4(7.8)	13(14.6)		
ID (yes)	13(25.5)	13(14.4)	2.64	.14
Financial difficulty (yes)	24(47.1)	27(30.)	4.10*	.17
Medical comorbidity (yes)	45(88.2)	67(74.4)	3.79	.16
Psychiatric comorbidity (yes)	45(88.2)	67(74.4)	3.79	.16
<i>Mesosystem</i>				
Community size			1.63	.11
Remote/rural	12(23.5)	14(15.6)		
Suburban	15(29.4)	33(36.7)		
Urban	24(47.1)	43(47.8)		
<i>Exosystem</i>				
Barriers	4.35(2.38)	2.37(1.97)	5.33***	0.91

^a *n* = 51; ^b *n* = 90

* *p* < .05; ****p* < .001

Table 2.10.

Simple Linear Regressions Modeling Total Service Use (n = 141)

Variable	<i>B</i>	SE	β	<i>t</i>	<i>p</i>
<i>Microsystem</i>					
Women (vs. Men)	0.16	0.25	0.05	0.62	.54
Age	-0.03	0.01	-0.20	2.39	.02
Education ^a					
College diploma (vs. High school)	0.24	0.22	0.08	0.77	.45
Undergraduate degree (vs. High school)	0.05	0.35	0.01	0.13	.89
Graduate or professional degree (vs. High school)	-0.24	0.43	-0.06	-0.57	.57
ID (vs. no ID)	0.43	0.32	0.11	1.36	.18
Financial difficulty (vs. no financial difficulty)	-0.01	0.26	-0.01	-0.06	.96
Medical comorbidity (vs. no comorbidity)	0.07	0.31	0.02	0.22	.83
Psychiatric comorbidity (vs. no comorbidity)	1.15	0.30	0.31	3.90	<.001
<i>Mesosystem</i>					
Community size					
Suburban (vs. remote/rural)	0.29	0.37	0.09	0.81	.42
Urban (vs. remote/rural)	0.17	0.35	0.06	0.50	.62
<i>Exosystem</i>					
Service barriers	0.09	0.05	0.13	1.59	.12

^a *n* = 140

Table 2.11.

Multiple Regression Modeling Total Service Use (n = 141)

Step	Variable	B	SE	β	<i>t</i>	<i>p</i>
1	Constant	2.07	0.27		7.70	<.001
	Women (vs. Men)	-0.04	0.24	-0.01	-0.15	.88
	Age	-0.03	0.01	-0.19	-2.32	.02
	Psychiatric comorbidity	1.13	0.30	0.31	3.78	<.001
2	Constant	2.37	0.30		7.80	<.001
	Women (vs. Men)	-1.05	0.59	-0.35	-1.79	.08
	Age	-0.01	0.02	-0.09	-0.72	.48
	Psychiatric comorbidity	0.71	0.36	0.19	1.97	.04
	Sex/gender X Age	-0.12	0.02	-0.10	-0.83	.41
	Sex/gender X Psychiatric comorbidity	1.23	0.64	0.41	1.91	.06

Note:

Step 1: $R^2 = .13$; $F(3,137) = 7.01, p < .001$

Step 2: $R^2 = .16$; $F(5,135) = 5.21, p < .001$

Table 2.12.

Simple Poisson Regressions Modeling Total Unmet Service Needs (n = 141)

Variable	<i>B</i>	SE	OR(95% CI) (Exp <i>B</i>)	Wald χ^2	<i>p</i>
<i>Microsystem</i>					
Women (vs. Men)	0.23	0.15	0.80(0.59, 1.07)	2.31	.13
Age	0.01	0.01	1.01(1.00, 1.03)	3.96	.05
Education ^c					
College diploma (vs. High school)	-0.25	0.19	0.78(0.54, 1.13)	1.76	.19
Undergraduate degree (vs. High school)	-0.06	0.20	0.95(0.64, 1.39)	0.08	.77
Graduate or professional degree (vs. High school)	-0.30	0.27	0.74(0.44, 1.26)	1.22	.27
ID (vs. no ID)	0.01	0.19	1.01(0.69, 1.48)	0.01	.94
Financial difficulty (vs. no financial difficulty)	0.58	0.15	1.79(1.33, 2.40)	14.85	<.001
Medical comorbidity (vs. no comorbidity)	0.45	0.22	1.57(1.03, 2.41)	4.43	.04
Psychiatric comorbidity (vs. no comorbidity)	0.45	0.22	1.57(1.03, 2.40)	4.42	.04
<i>Mesosystem</i>					
Community size					
Suburban (vs. remote/rural)	-0.45	0.22	0.64(0.42, 0.97)	4.41	.04
Urban (vs. remote/rural)	-0.14	0.19	0.87(0.60, 1.27)	0.51	.48
<i>Exosystem</i>					
Service barriers	0.13	0.03	1.14(1.07, 1.21)	17.82	<.001

^a *n* = 140

Note: OR = Odds Ratio; CI = Confidence Interval

Table 2.13.

Multivariate Poisson Regression Modeling Total Unmet Service Needs (n =141)

	Variable	<i>B</i>	SE	OR(95% CI) (Exp <i>B</i>)	Wald χ^2	<i>p</i>
1	Intercept	-0.06	0.31	0.95(0.52, 1.73)	0.03	.86
	Women (vs. Men)	-0.03	0.16	0.97(0.71, 1.33)	0.04	.84
	Age	0.01	0.01	1.01(1.0, 1.03)	3.36	.07
	Financial difficulty (vs. no financial difficulty)	0.42	0.17	1.52(1.10, 2.11)	6.48	.01
	Medical comorbidity (vs. no comorbidity)	-0.00	0.24	1.00(0.62, 1.61)	0.00	.99
	Psychiatric comorbidity (vs. no comorbidity)	0.16	0.24	1.18(0.74, 1.86)	0.46	.50
	Community size					
	Suburban (vs. remote/rural)	-0.24	0.22	0.79(0.51, 1.22)	1.14	.29
	Urban (vs. remote/rural)	0.03	0.19	1.03(0.70, 1.51)	0.02	.89
	Service barriers	0.11	0.04	1.11(1.04, 1.19)	9.27	.002
2	Intercept	-0.05	0.31	0.95(0.52, 1.77)	0.02	.88
	Women (vs. Men)	-0.03	0.22	0.97(0.63, 1.50)	0.02	.90
	Age	0.01	0.01	1.01(1.0, 1.03)	3.36	.07
	Financial difficulty (vs. no financial difficulty)	0.41	0.25	1.51(0.93, 2.46)	2.77	.09
	Medical comorbidity (vs. no comorbidity)	0.00	0.24	1.00(0.62, 1.62)	0.00	.99
	Psychiatric comorbidity (vs. no comorbidity)	0.15	0.24	1.16(0.73, 1.85)	0.39	.53
	Community size					
	Suburban (vs. remote/rural)	-0.24	0.22	0.79(0.51, 1.23)	1.11	.29
	Urban (vs. remote/rural)	0.03	0.19	1.03(0.70, 1.51)	0.02	.89
	Service barriers	0.12	0.06	1.13(1.01, 1.26)	4.19	.04
	Sex/gender X Financial difficulty	.01	0.32	1.01(0.54, 1.89)	0.01	.97
	Sex/gender X Service barriers	-0.02	0.07	0.98(0.85, 1.11)	0.07	.79

Note: OR = Odds Ratio; CI = Confidence Interval

Step 1: $\chi^2(8, N = 141) = 32.99, p < .001$

Step 2: $\chi^2(10, N = 141) = 33.06, p < .001$

Table 3.1.

Codes According to Candidate Themes

1.1	1.2	2.1	2.2
Don't fit into any social group; Not the cookie cutter ASD symptoms; Need for self-initiative in ASD assessment services; Lack of understanding/awareness of ASD; Adults don't need ASD diagnosis; Difficult to find assessment services as an adult; Missed diagnoses lead to missed opportunities; Families don't understand ASD diagnosis; ASD diagnosis opens doors to self-understanding	Masking ASD symptoms; Too high functioning /presenting well to get services; Emotional costs of social interactions; Anxiety of putting yourself out there; Feeling ashamed for asking for help; Unable to fulfill gender norms when seeking services; Being mistreated/ taken advantage of; Imploding and exploding; Perceived stigma of asking for help	Difficulty communicating needs; Feeling rushed/no time to explain needs; Service providers' perceived minimization of pain/needs; Tendency to minimize own pain/needs; Dismissiveness of everyday exhaustion; Feeling accepted/heard; Difficulty explaining/understanding sensory sensitivities	Services just don't exist; Waitlists are too long; Transportation services needed; Need help with paperwork; Lack of service coordination; Advocacy support needed; Social Anxiety as service barrier; Financial barriers; Excluded due to sex/gender; Excluded due to age, Excluded due to cognitive abilities; Geographical barriers; Overqualified and underemployed; Services don't reflect strengths; Reactive vs. proactive services; Individualized mental health supports needed; Need for structured social supports; Importance of online supports

Note: The following codes were classified as "Miscellaneous" and not included in the final analysis: Dangers of self-disclosure on the job; Childhood bullying

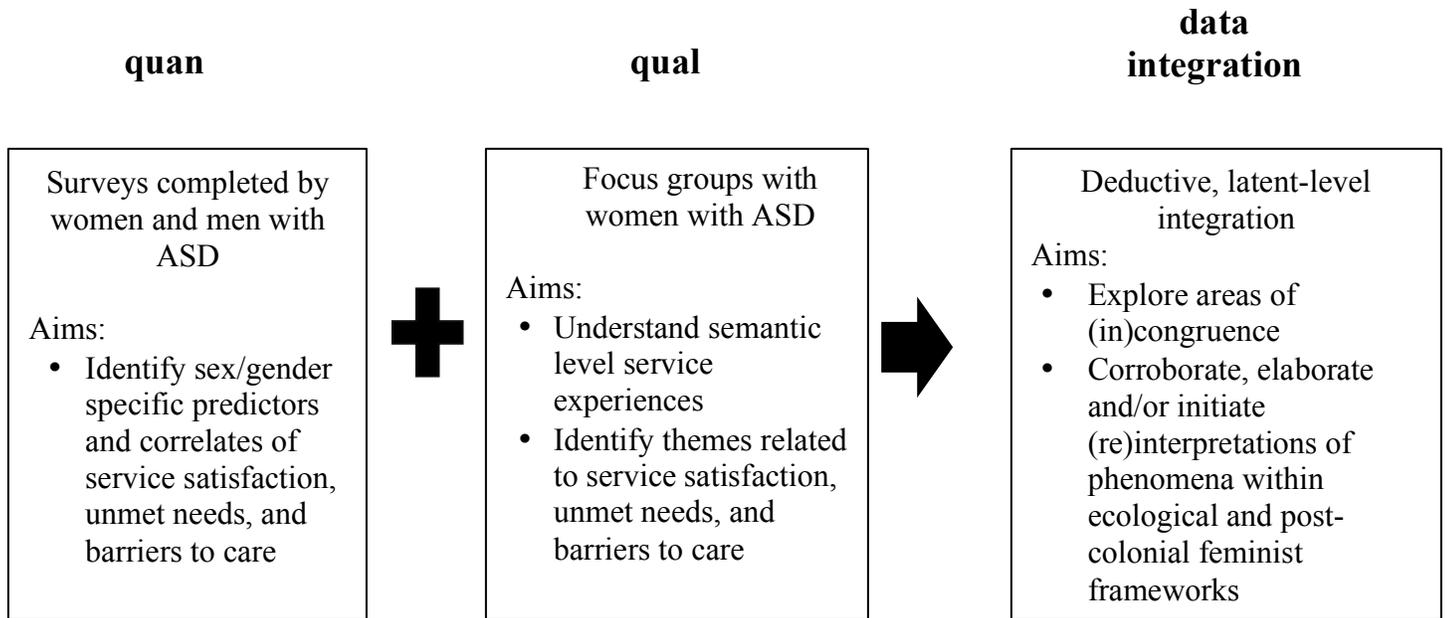
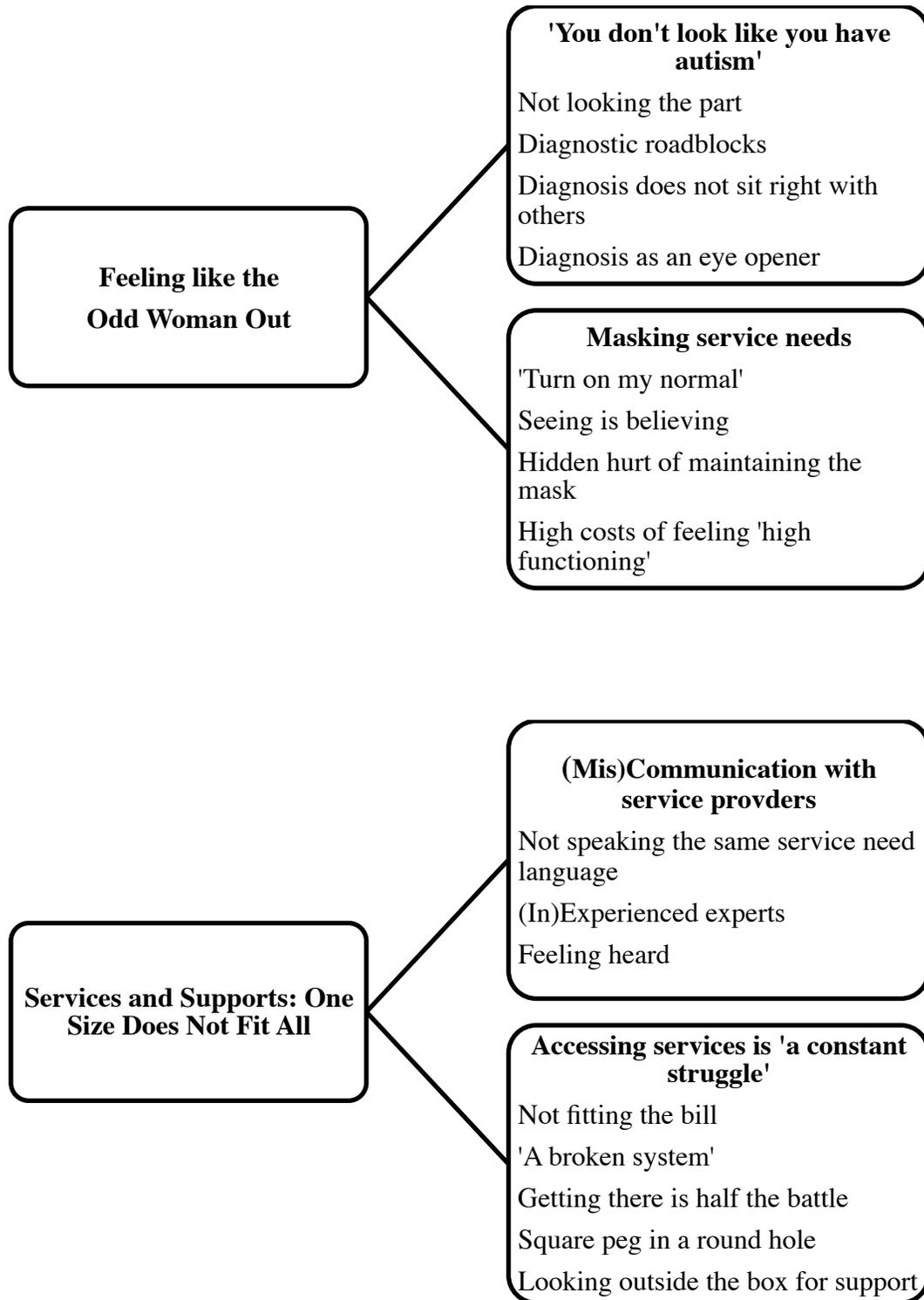


Figure 1.1 Project design

Figure 3.1 Thematic map



APPENDIX A

Demographic Questionnaire

Information about you:

Age:

Ethnicity:

Relationship status:

Employment status:

Highest degree attained:

Where do you live (e.g., family home, in your own apartment/house)?

Who do you live with:

Age at ASD diagnosis:

Healthcare professional who gave ASD diagnosis (e.g., family doctor, psychologist):

APPENDIX B

Women with ASD Group Moderator Guide

Participants will be given consent forms and demographic questionnaires as they enter the room.

Ground rules

I'd like to thank you all for coming today. We're conducting a study about the service experiences of women with Autism Spectrum Disorder (ASD). We will also be holding similar groups with families of women with ASD to get their own perspectives as well. We're holding this discussion group today to get a sense of how you feel about your service experiences: what's working, what's not, and what could be done to make it better?

The way the group works is that I will start with some questions that I will ask you to respond to. You do not need to respond in any particular order amongst yourselves, feel free to have an open conversation. Please keep in mind that there are no right or wrong answers - I just want to get some idea about your opinions and experiences.

If you have a different opinion than someone else, please feel free to say so. All I ask is that you give everyone a chance to state their views - and it helps if only one person is speaking at a time. Because I have a number of issues I want to discuss with you today, I may have to occasionally ask the person speaking to cut short their answer to keep things moving and ensure that we finish on time.

Everything you say will be kept strictly confidential and I ask that you refrain from commenting on what others discussed in the group when you leave here today. I want to remind you that our discussions will be audio recorded because it is difficult for me to write extensive notes and follow the discussion at the same time, but your names will not appear anywhere in our results. I'd like to hear the experiences and opinions of everyone here today, but if you feel that you cannot answer a question or do not want to, you can feel free to remain silent at any time.

(Run through where washrooms are located, approximate time group should end, etc.)

Are there any questions before we begin?

Ensure all participants have completed the consent form.

Introductions

Ask each person to give their first name and to share a bit of information about themselves (name, age, where they live, etc.). Begin by introducing yourself and your background.

General questions on service use and needs

1. I'd like to get some initial feedback on your general feelings about the services you are currently receiving or have used in the past year. When I say services, I mean any formal or professional support like a doctor, therapist, group home, job coach, etc.. Who would like to start?
2. What are some services that she is NOT currently receiving but would be helpful?

PROBE: Probe to try to get a bit of detail from each person (e.g., Anything else? Anyone else?)

Specific service experiences

3. (We touched on some of these things a bit already, but) I'd like to talk a bit more about some specific services now:
 - a. This may have been a while ago for some, but can you tell me a bit about your experiences with the **ASD assessment** or diagnostic process?

What have been your experiences with:

- b. **health services** (family doctors, gynecologists and other specialists, dentists, hospitalizations)?
- c. **mental health services** (therapists, counselors, psychologists, psychiatrists)?
- d. **social skills services** (social skills groups, facilitated social interactions)?
- e. **post secondary educational and vocational supports** (day programs, university and college-based services, job coaches)
- f. **residential supports** (group homes, semi-independent living services)
- g. **family support services** (respite care, family support groups)?

PROBE: What was positive about the (service) experience? What was negative about the (service) experience? How did you feel the (service provider) treated you? Would you recommend this (service provider) to a friend with similar needs? Anyone have similar or different experiences?

Barriers to care

4. Now, thinking about some of the services that you mentioned earlier that you or your family member are not currently receiving but would be helpful, what sorts of things are preventing you from accessing or receiving them?

PROBE: What sorts of personal or family factors are impacting the services you are (or are not) receiving? What sorts of structural or policy issues are impacting the services you/your family member with ASD are (or are not) receiving?

Suggestions for Improvement

I'd like each of you to make one comment or reflection on what would be the most important thing, from your perspective, that could improve services for women with ASD? Let's just go around the table. (*Name of person to left or right*), can I begin with you?

PROBE: What sort of programs do women with ASD and their families need? What do service providers need to know about women with ASD and their families?

Summary

We're almost finished but before we end, I want to try to summarize some of the things we discussed today to make sure I understood all of you correctly.

(read summary notes)

Did I misunderstand anything you said? Did I miss anything? Are there any final comments you would like to make on this topic?